Families in Program and Policy
FiPPs MCH Report

Interviews on Family Participation with State Title V Maternal and Child Health Programs

FAMILY VOICES®
... speaking on behalf of children and youth with special health care needs

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Interviews on Family Participation with State Title V Maternal and Child Health Programs

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Report compiled and completed 2005

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Families in Program and Policy

FiPPs MCH Report

A Report of Interviews with MCH Programs about the Participation of Families in Title V MCH Programs, 2002

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ACKNOWLEDGMENTS

Family participation with program and policy activities has been the result of the inspiration, co-operation, and hard work of many groups and individuals over many years. Significant progress has been made; it seemed evident that a study of this sort would be of great interest and use.

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In addition, we were very fortunate to have the thoughtful input from members of the MCHB staff who worked with us to identify questions and topics of greatest relevance to State MCH Programs – Trina Anglin, Pete Conway, David Heppel, Joe Leach, Ann Koontz, and Phyllis Stubbs.

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FAMILY VOICES

Family Voices is a national organization of families and friends speaking on behalf of children and youth with special health care needs (CYSHCN). Our mission is to advocate for health care services that are family-centered, community-based, comprehensive, coordinated, and culturally competent for all children and youth with special health care needs; promote the inclusion of families as decision makers at all levels of health care; and support essential partnerships between families and professionals.

Family Voices operates many projects to improve the health and well-being of children and families. The *Family Voices* organization consists of family leaders in every state, supported by staff in Arizona, California, Illinois, Iowa, Massachusetts, New Mexico, North Carolina, and Texas.

Many groups focus on particular childhood illnesses or populations; others represent children and adults or concentrate on specific health topics. Until *Family Voices* formed, there was no national organization that spoke for all children and youth with special health needs, regardless of diagnosis - a population estimated at over 9 million children under the age of eighteen.

Catalyzed by the 1992 presidential campaign efforts on health care reform, families across the nation began to explore the creation of a national organization focusing on children and youth with special health care needs with the goals of improving systems of care and providing family-friendly information to families. *Family Voices* formed in December, 1992. It was soon evident that this national network of families and friends filled an enormous need for information, expertise, partnership, and support, not only for families, but also for professionals and policymakers.

Early funding from the Maternal and Child Health Bureau and the Robert Wood Johnson Foundation, and later from the Annie E. Casey and the Packard Foundations, among others, helped *Family Voices* to provide assistance and resources to state *Family Voices* leaders, allowing them to partner with professionals. National and regional *Family Voices* conferences provided crucial opportunities for building family leadership and promoting family knowledge and involvement in many child health initiatives.

Family Voices has become a vibrant organization with active members in every state, whose knowledge, perspectives, and influence are respected and frequently sought, to participate in shaping programs and policies. *Family Voices* has produced materials for families and family leaders. Findings from *Family Voices* research projects have been published in professional journals. *Family Voices* provides technical assistance to Family-to-Family Health Information Centers as well as to volunteers throughout the country. *Family Voices* supports the empowerment of youth with special health care needs through Kids as Self Advocates (KASA).

Additionally and of special relevance to these interviews with MCH Programs, *Family Voices* has also begun to address issues for children with special health care needs in "the wider world of children." The very broad definition of children with special needs[1] includes children with a wide range of conditions, most seen for at least some of their health care in "regular" health settings. Public health concerns embodied in preventive/well childcare apply equally to our children. Health and wellness is addressed through *Family Voices*' Bright Futures publications and initiatives funded by MCHB and the Centers for Disease Control and Prevention (CDC). While the Division of Services to Children with Special Health Care Needs at MCHB has special relevance to *Family Voices* and the children who are our special focus and concern, other divisions and programs at MCHB, notably the Division of Child, Adolescent and Family Health, with its focus on that "wider world of children," for this reason merits our attention.

[1] *Children who have or are at increased risk for a chronic, physical, developmental, behavioral, or emotional condition and who also require health related services of a type or amount beyond that required by children generally.* — Division of Services to Children with Special Health Care Needs, Maternal and Child Health Bureau.

INTRODUCTION

Acknowledgment of the role of families as critical partners with professionals in program and policy activities has been an important shift in health care delivery and is now well accepted in many spheres. While the Maternal and Child Health Bureau (MCHB) has referred to the philosophy of family-centered care and its relevance for all families, it was in 2002 that the MCHB Strategic Plan included the phrase, "to promote and support the development of family-centered, culturally competent, community-based systems of care nationwide for CSHCN, *and the entire MCH population*" (italics added). This last is the purpose of our inquiry – to learn more about the ways families and family organizations are involved with Title V Maternal and Child Health (MCH) State Programs.

In 2001 – 2002, *Family Voices'* Partners in Information and Communication Project (FV PIC), funded by the Division of Child, Adolescent and Family Health (DCAF) at MCHB, conducted a study of MCH Programs to document family involvement with these programs. The study was undertaken jointly with the Family-to -Family Health Information Project, *Family Voices*, funded by MCHB Division of Services to CSHCN. The interview expanded on several earlier initiatives. A previous interview in 1992 sought to determine the kinds and amounts of participation by parents and other family members with state Title V CSHCN programs[2] on a variety of dimensions. In 1993 a further investigation of the numbers and roles of family members employed by CSHCN Programs was undertaken[3]. In turn, these investigations had been preceded by an inquiry in 1987 about parent participation on advisory committees in MCH and CSHCN Programs[4].

Information in this report was collected from State Title V MCH Programs through telephone interviews conducted by trained family leaders. The interview questionnaire asked respondents about their overall experiences with family involvement and their specific experiences in a number of areas. Areas included the participation of families on committees, in-service training, the Title V Block Grant process, and with initiatives to improve maternal and child health and State Performance Measures. Information was also gathered about relationships with families and family organizations and support provided for their involvement, employment of family members and outreach to underserved populations. Similar information was collected from CSHCN programs and is summarized in a companion report, Families in Program and Policy, FiPPs CSHCN Report. Additionally, programs were asked to contribute materials supporting the involvement of families in their programs for a "web repository." *The Family Voices Title V Toolbox for Family Participation* (www.familyvoices.org/toolbox) is the result and a summary of these resources is also included in this report.[5]

Responses received from MCH Programs provide, as anticipated, an extremely interesting picture of the "state of family participation" and further, suggest directions for the future. This report provides findings from each of the topic areas investigated as well as ideas, materials and strategies. The report will be useful to those involved in national, state and local planning and policy activities, particularly for state and family leaders who continue daily to create the partnerships that provide such critical roles in improving maternal and child health and assuring quality of care for children and their families.

[2] This earlier project was carried out by the CAPP (Collaboration Among Parents and Professionals) National Parent Resource Center Project at the Federation for Children with Special Needs. Findings are summarized in a publication, **Families in Program and Policy: Report of a 1992 Survey of Family Participation in State Title V Programs for Children with Special Health Care Needs.** Wells, N., Anderson, B., Popper, B., 1993.

[3] CAPP Project, Federation for Children with Special Needs, **Family Employment in State Title V Programs: Conference Proceedings and Survey Report**, Anderson, B., Popper B., and Wells N., 1995.

[4] **CAPP Report, Survey of Parent/Consumer Participation on Advisory Committees to State Health Departments and Private Hospitals**, 1987, Popper, B.

[5] The Toolbox was funded by the Division of Services to Children with Special Health Care Needs, MCHB.

Background: Title V Maternal and Child Health

Created in 1935 through the Social Security Act, Title V is administered through the Maternal and Child Health Bureau. The original purpose, "to improve the health of all mothers and children, including children with special health care needs," underlies all Title V programs, with activities evolving to meet the changing social and health needs of families and children.

While State MCH and CSHCN Programs have always involved families in some aspects of their programs, likely all would agree that it was in the 1980's when the role of families in Title V Programs began to be emphasized. At that time the MCHB Division of Services for CSHCN articulated and emphasized a central role for families in participating in the care of their own children as well as in providing guidance at the program and policy level. Support for family participation had been reinforced through many Division activities including: family participation in meetings, documents that articulated the value of family involvement, and funded projects that emphasized roles for family members. In 1989, the Omnibus Budget Reconciliation Act (OBRA), mandated that CSHCN programs supported by MCHB work toward providing "family centered care" that is community based, coordinated, and culturally competent. OBRA provided guidelines requiring states to indicate their commitment to family centered care. Effective partnerships with families have been considered central to realizing this goal.

In the 1990s MCHB added questions to States' Title V Block Grant reporting requirements about how they would rate their State on involvement of families in Title V CSHCN programs and policies (Performance Measure 14, now Form 13: Characteristics Documenting Family Participation in CSHCN Programs).

In 2002 MCHB expanded the concept of family centered care beyond CSHCN Programs to *all MCH Programs* and further included in the MCHB Principles two that speak to the importance of relationships with families in MCH Programs[6]:

- The health, safety and well-being of the MCH population are best assured when there is an MCH/family focus within health systems and services.
- Family and community participation and engagement are crucial to the development of effective, quality health systems and services.

Acknowledgment of the important role of families and the conceptual framework for collaboration with families is present in MCHB principles, although there are not yet the kinds of reporting requirements about families for MCH Programs that are presently required of CSHCN Programs.

Family Voices, with its strong national network of families and family leaders in every state, has added momentum to Maternal and Child Health Bureau efforts. Through the creation of highly effective methods and vehicles of communication, training, and support and by strengthening collaborative relationships between families and public and private providers and policymakers, *Family Voices* has fueled the growth of family leadership and family involvement with many partners and systems, including Title V Programs.

[6] Maternal and Child Health Bureau, FY 2003-2007, Mission, Vision, Strategic Plan

METHODOLOGY

The idea of carrying out interviews with MCH Programs to obtain baseline information on family participation and updating interviews with CSHCN Programs evolved over time. Increasingly we learned of activities involving families in State MCH Programs. Further, the interviews we had carried out with State CSHCN Programs were now ten years old. It seemed time to obtain a current picture of family participation with both State MCH and CSHCN Programs. The interviews were conducted as a joint project. The MCH interviews were funded as an activity of the *Family Voices* PIC Project. Additional funding was sought for the CSHCN interviews by the *Family Voices* Family-to-Family Health Information Center.

This report summarizes the information collected through telephone interviews with fifty-one MCH Programs and documents their progress with implementing family involvement in their Programs. A companion report of the CSHCN interviews is available from *Family Voices*. A summary Chart on page 35 compares key information collected from the MCH and CSHCN interviews.

Introductory information provided guidance to respondents. For example, "families" were defined as relatives, guardians, and foster families as well as parents and siblings. "Family/family organization involvement in program and policy activities" was described as "family members or groups who advise or assist the Title V program in understanding needs and providing quality care and services for children and families." States were asked to specifically report the efforts their programs make to include family members from a diverse range of socio-economic, racial, cultural, and ethnic backgrounds. They were asked to give their responses for activities occurring in the preceding 12 months. Respondents were sent the questionnaire ahead of time and were asked to be ready to respond verbally - they were not asked for written responses. Participants were asked to focus their answers based *only on their MCH Program* and were reminded that similar questions were being asked of their CSHCN colleagues. They were encouraged to include other staff in the phone interview if they wished.

Questions for the MCH and CSHCN interviews were nearly identical, with only a few designed differently to reflect specific programs and requirements. We began with the base of questions asked of CSHCN programs in 1992 and 1993, which in turn had expanded on a 1987 survey on parent involvement on advisory committees. The 1992 questionnaire had been developed with the input of experienced parent leaders who suggested areas of information that might be useful to know about family participation. For the 2002 initiative, the 1992 questions were revised and expanded through review by project staff, discussions with MCHB staff and *Family Voices* Network Members, and the advice of an Advisory Committee of parents and professionals. The tool was then piloted in four states, and revisions were made based on field experience.

Telephone interviews, lasting approximately one hour each, were conducted by twelve parent leaders who had been recruited nationally. The strategy of phone interviews was chosen because we believed it important to create an opportunity for discussion on these topics and because it was felt it would result in greater participation. Each interviewer was prepared through group conference calls and individual technical assistance and provided with follow up support from project staff. Detailed step-by-step memos and specific background material was sent, such as State Negotiated Performance Measures and State organization charts, for the States for which they were responsible. Telephone calling cards were supplied by the project. Parent interviewers completed the phone interviews and submitted written summaries which were then sent to MCH Program staff for clarification and approval. At least three attempts were made to solicit feedback; those interviewed had been told that after a certain time period their approval would be assumed. Thirty-seven responses, some with suggested edits, were received.

continued

MCH Directors were prepared for the interviews in several ways: a postcard announcement; a display at the annual Association of Maternal and Child Health Programs (AMCHP) conference; and a direct mailing that included the interview tool and letter of explanation. Interview materials were also posted on the *Family Voices* website. Fifty-one MCH programs completed the interview protocol; only two, Alaska and the Virgin Islands, did not. The fifty-one included forty-nine States, one Territory (Puerto Rico) and the District of Columbia. In thirty-five states the interview was carried out with the MCH Director; the others were conducted with program staff designated by the Director. In twelve interviews more than one person participated.

This report provides a snapshot of family participation as reported by the MCH Director or designee at the time of the interview. Responses were obviously dependent on the knowledge of the person interviewed and may also be dependent on individual interpretation of certain questions. Several interviewers noted the candor and openness of the respondents, particularly in terms of comments that might be seen to reflect negatively upon programs. More than a dozen questions had open-ended components. Since this was a discussion interview, many additional comments of a qualitative nature were obtained, greatly enriching the quantitative information. However, in a few cases they contradicted information provided in quantitative questions. Nevertheless, the information provides a vivid picture of numerous activities involving families and interesting models and ideas to stimulate further thinking and next steps. Finally, some State activities have certainly changed since the information was collected.

This report includes narrative discussion, graphs of findings for the areas of information collected, quotations and examples from States, as well as state-specific tables of responses. The questionnaire used with MCH Programs is also included. Phrases and sentences in italics with bullets are quotations from respondents. Quotations and qualitative information are summarized without reference to specific states, as had been stipulated beforehand, and have been "lightly edited" for readability.

SUMMARY OF FINDINGS

All State Title V MCH Programs interviewed indicate involvement with families in program and policy activities in 2001 - 2002. There is, however, considerable variation in the kinds and amounts of activities, with some States involving families in many activities, while in others family participation is limited to only one or two initiatives. Of particular interest are those activities in States relating to "State Performance Measures" and those relating to "Initiatives to Improve Maternal and Child Health," both of which seemed to offer States a wide range of opportunities to involve families. (n = number of State MCH Programs that responded to interviews.)

Chart 1. Summary Findings: 2002

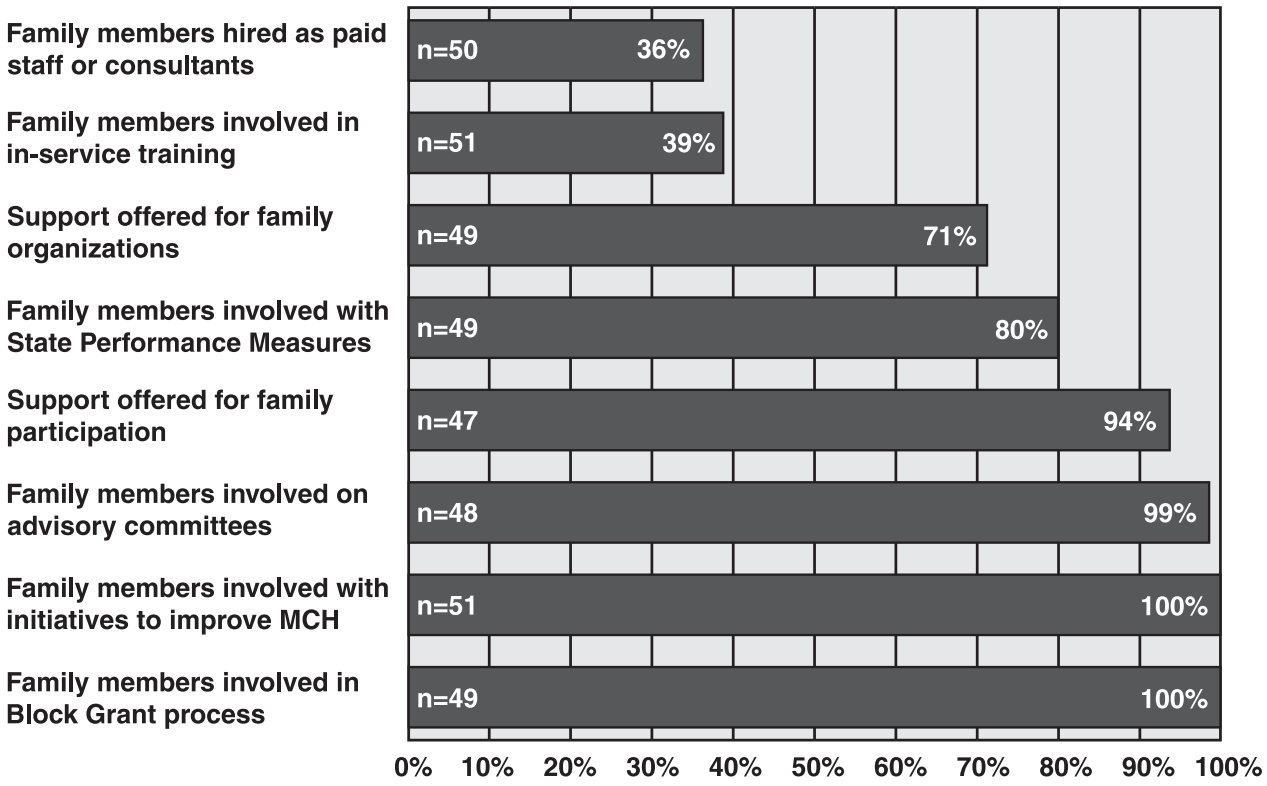


Chart 1 offers a summary of the ways MCH Programs said they involve families in several key areas. In several areas – Block Grants (100%); initiatives to improve MCH (100%) – see pages 20-21 for specifics; advisory committees and task forces (99%); and support offered for family activities (94%); most States indicate significant family involvement. In other areas - hiring family members as staff or consultants (36%); family participation in in-service trainings (39%); support for family organizations (71%); and State Performance Measures (80%); families are less in evidence.

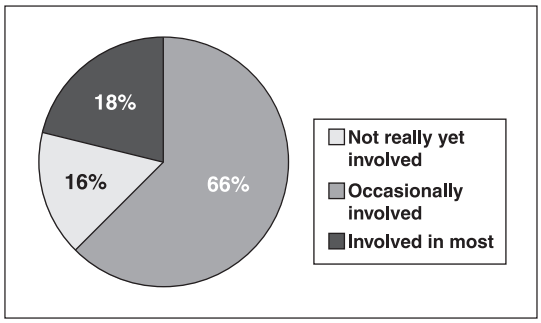
There is an interesting discrepancy between the support that States say that they offer to family members who participate in various ways (94%), and the support they provide to family organizations, which is considerably less (71%).

It should be noted that the questions asked were whether families were involved – not how many families or how often - so this is a beginning picture, indicating that the majority of State MCH Programs involve families in a number of ways.

Overall Family Involvement in MCH Programs

The initial question asked State MCH Programs to indicate the extent to which families are part of program and policy activities with their MCH Program.

Chart 2. Family Involvement in MCH Program & Policy Activities (n=50)



While most States indicated that families are occasionally involved (66%), the remaining Programs were split almost evenly between those that involved families in most activities (18%) and those saying families were really not yet involved with their programs (16%). Although for this last figure it should be noted that as more specific questions were asked, virtually every Program noted family involvement in some aspect of their activities. Comments expressed by State MCH Programs indicate that while they appreciated the value of family involvement, they were not always sure how to achieve it for their programs. A number mentioned CSHCN programs as models, but others commented that their programs were different and need other approaches. Several said that it would be helpful if it were required in the Block Grant.

Key Ways Families are Involved

As might be anticipated from the above question, responses from States varied considerably as to the key ways families were involved with their MCH Programs. Some listed rich and varied involvement; others described participation in just a few of their programs. Responses to this question also elicited a number of thought-provoking comments, which are highlighted below. (n=50)

States indicated that family involvement is often by specific activity or program and may occur at any or all levels – state, county, and/or community. Most frequently MCH Programs mentioned that families are involved in advisory committees and coalitions – giving many specific examples such as SIDS, epidemiology, prenatal coalitions, women's health, family planning, screening, abuse, immunization, abstinence, child health, and more. Some States gave examples of committees chaired by parent members. A few Programs indicated that they had regional advisory groups that made it easier for them to involve families from different areas of their States.

Educational conferences were also described, with some saying that families often serve as presenters. Other MCH Programs said they provide training, including training on policy issues, for families.

Several States said that family involvement is sometimes required; one State offered the example of their Community Health Centers for which fifty-one percent must be community members but noted that "not all of these are parents." A few States described Commissioner or legislatively-created committees with one State saying "by law one-third of its members are consumers."

Activities relating to diversity and cultural competence were areas mentioned by several States, with many mentioning outreach as a key

One State, below, noted:

- *Our MCH Program funds 10 communities to organize services for families with young children and these projects include families.*
- *Local family planning programs are required to have community education programs which include families and review of materials.*
- *School-based Health Centers have parents and students involved on advisory committees.*
- *The abstinence-only education program grantees have advisory committees, many with family representation.*
- *The Healthy Start Consortium includes family members.*

activity. Some Programs said they involve families to review materials for specific cultural groups.

Publicity and outreach were also mentioned by States as activities in which they involve family members – outreaching to other families, designing television and billboard ads, and planning outreach initiatives.

Adolescent involvement was mentioned in many Programs – teen pregnancy and substance abuse, among others. One mentioned that their Program involves teens as facilitators for some projects. Participation of fathers was also described by some Programs, especially in parenting initiatives. (The interviews did not specifically inquire about either adolescents or fathers.)

Some States described involving families in special projects to address a variety of short and long term initiatives – SCHIP, a Children's Health Diary, as examples. Others specifically mentioned involving WIC families, in part because they come in frequently, making it easy to establish relationships, and also they typically represent the diversity of populations that MCH Programs serve. Finally, a small number of Programs, typically those with more significant family involvement, mentioned employing families.

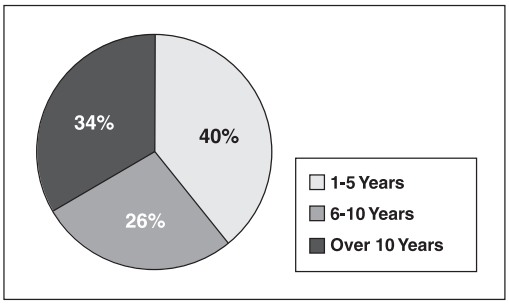
Involvement with families has been a very interesting, complex, sustained influence on our whole division and the department, as well as on the behavior of our staff.

We are continually networking with families to obtain representatives of diverse ethnic and gender balance on all committees in the department.

History of Family Involvement

MCH Programs were asked to indicate how long family members have participated in their programs.

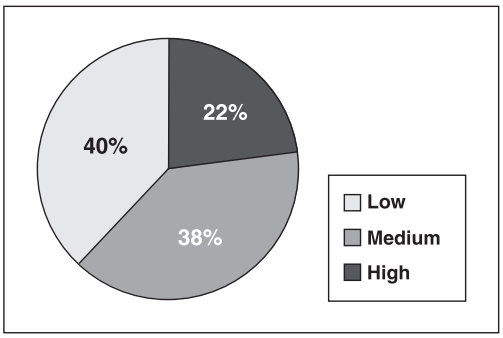
Chart 3. History of Family Involvement in MCH Programs (n=50)



As can be seen in Chart 3, for most Programs (40%) family involvement is relatively recent. Twenty-six percent said participation has occurred for six to ten years, and 34% percent said families had been involved for over ten years.

Early Intervention as an Influence

Chart 4. The Degree to Which Family Involvement Has Been Influenced by EI Activities (n=45)



MCH Programs might be thought to be less influenced by Early Intervention (EI) policies and practices than CSHCN Programs. We asked this question because in approximately two-thirds of States Early Intervention is organizationally located in the same department as the Title V Program. Family involvement is significantly included in the language of EI legislation, policy and practice.

As indicated in Chart 4, while only 22% of MCH Programs said they were highly influenced by Early Intervention Programs, the others were nearly split; with 38% saying there was a medium influence and 40% indicating it was a low influence.

- *The local programs have a stronger component for family involvement.*
- *We apply for the federal grant and then we in turn make this grant available for small grants for community agencies to help in their family strengthening activities. One of the parameters for the grantees that apply is that they must have families involved in their organizations.*

Community Level Activities

A general theme throughout MCH interviews was how much of their activity involves direct service and takes place at community levels. A number expressed concern at not having much, or even any, family involvement at the State level, although interview questions did not specify or place a value on the level or location of family activity. Some respondents knew of activities occurring in the community but weren't always knowledgeable about the specifics. Further, as will be noted, family participation sometimes occurred at a distance from the respondent, through agency contractors. While in some instances States had recognized the importance of family involvement enough to stipulate it in contracts, this was not always the case.

- *Several of our programs require consumer representation, evaluation, or input – WIC, family planning, child care, and school-based centers.*
- *We have contracts for home visiting programs throughout the state and we require in the contract that families be involved in the planning of those programs.*

Contracts

Many MCH Programs described contracts as a significant vehicle for services, with some mentioning dozens and one saying they had over 350 contracts or agreements. Slightly more than half (55%) of the 49 MCH respondents said they utilize contracts as a vehicle for the delivery of services and more than thirty offered comments about them. In States where this occurs, there seems an opportunity to address family participation, which some Programs mentioned. By contrast, others seemed to feel somewhat removed from contracted activities, with one saying, "It's hard to get information on family involvement from direct-service providers, for example, Family Planning."

However, another State noted that "there is not a lot of contractual language that imposes family involvement on the community system." In States where this is not being done there may be a particular reason, or perhaps, it is not a priority.

Finally, an interesting point made by one Program is that contracts commonly say "community members" which often - although not always - means families.

In the future we would like to specify participation by family members in various MCH programs, rather than CSHCN parents being the representatives for all.

CSHCN Programs as a Touchstone for Family Participation

A number of MCH Programs mentioned that in their States, MCH and CSHCN are organizationally in the same division or department and said that they work very closely together. In other States this seemed not to be the case. For many MCH Programs, CSHCN seemed to set the standard for family participation. Many commented on their use or adaptation of methods used by their CSHCN colleagues. Some MCH Programs compared themselves unfavorably in terms of what CSHCN has been able to accomplish and expressed envy at families' contributions to CSHCN efforts. As has already been noted, at times during the interviews respondents had to be drawn back to focus on MCH since discussions of family involvement so naturally led to discussion of initiatives within CSHCN Programs.

On the other hand, some MCH Programs expressed a desire to have "their own families" who could represent or speak more to MCH issues. And many programs said they hoped for models or strategies that would work for their MCH Programs, such as:

- How non-CSHCN Programs can better involve parents on achievement of performance measures.
- Successful models of broad-based support for involving families.
- Ideas on how to involve families in "normal" maternal and child health issues.

We're at the beginning stages of bringing families into MCH Program planning. We're talking with managers about an MCH vision for family involvement. Staff already use the parent hired for the CSHCN Program to get ideas about how families can be involved in MCH Programs.

Characteristics of the MCH Population

Among the themes that emerged from open-ended discussions with MCH Programs were two that seemed especially significant. The first was that MCH largely serves populations that are vulnerable and perceived as less likely to be "middle class" than families served in CSHCN Programs. While Title V is charged with serving "all mothers and children," the reality as expressed by some MCH Programs is that they serve a preponderance of low income families. A second theme was that MCH Programs typically focus many of their initiatives on prevention, which some saw as a more challenging area in which to engage families' active interest.

- *Interested in hearing tips on involving lower socio-economic families who are struggling to get by day to day.*
- *For the typical MCH population we are talking about primarily low income, low educated families.*

Comments Expressing Discouragement

Judging by the comments and tenor of the interviews, MCH Programs recognized the value of involving families; however, many expressed discouragement or dissatisfaction with the success of their strategies.

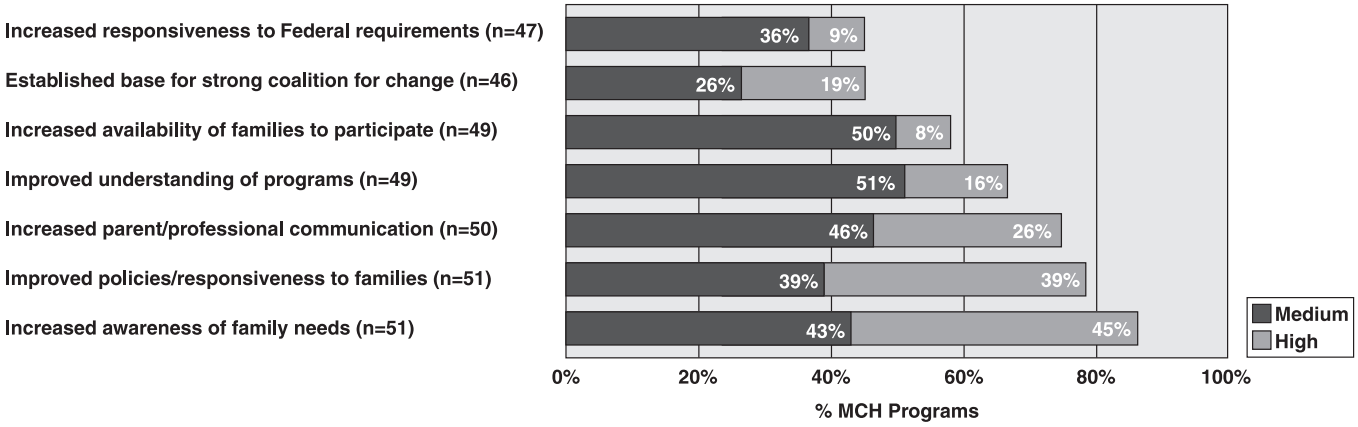
- *We also have a fair number of prevention-oriented programs. It's harder to think about family involvement.*
- *We'd like to hear from others about how they do it and what the benefits are. It is less clear to me how to involve families who receive prenatal care or whose kids go for child health care.*

- *We are good at recruiting but not good at retaining.*
- *Not effectively. And that is why we are very interested in collaborating with groups who might have contact at local and community levels that we can tap into.*
- *We have not had a lot of luck in recruiting families to participate in MCH-type activities.*
- *We've been paying for parents' time for a long time... it has not helped much.*
- *Have not really found a plan that works.*
- *We're still gaining experience... these are issues that need to be addressed.*
- *The MCH Program is just beginning to explore the potential role families may play in programming and development.*
- *We really haven't done so and we are not sure where to go with this issue.*

Benefits of Family Involvement to MCH Program

States were asked to indicate (low/medium/high) in any or all of seven areas in which family participation had benefited their Programs. (These areas were devised from open-ended responses to earlier interviews with CSHCN Programs.)

Chart 5. Benefits of Family Involvement to MCH Program



While responses varied, all respondents noted areas of contribution. Increased awareness and understanding of family needs was noted most frequently (88%), followed by improved planning and policies based on families' needs (78%) and increased parent – professional communication and understanding (72%).

Sixty-seven percent said family participation resulted in increased understanding of MCH Programs by state officials, the general public, or the legislature. Fifty-eight percent indicated that families were available to participate in training, public awareness, or policy development. Least noted were the areas of responsiveness to Federal requirements and establishing the basis for a coalition for change (both 45%).

Future Directions

Finally, some Programs expressed confidence and had moved beyond the beginning level of involvement and felt they had successful strategies to involve families; still others identified their needs in terms of involving families.

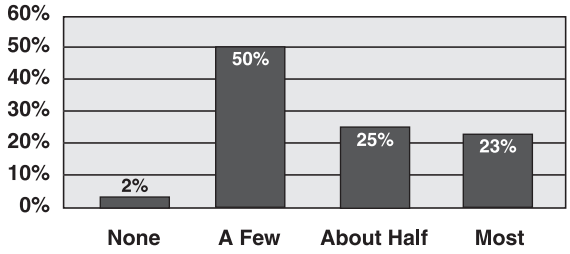
- We don't really need technical assistance; internal priority is needed. There is lots we can do by making the commitment.
- Every MCH Program in our State has a different level of involvement with families. We'd like to standardize the indicators of family involvement.
- We need more sessions at conferences to share strategies for family involvement from the family perspective…what it's like to receive services, how it feels. Family stories are so powerful and poignant. Their stories are what change policy.
- We'd like for family involvement to serve the whole population; to be more comprehensive in scope.

FAMILY INVOLVEMENT IN ADVISORY COMMITTEES

States were asked several questions about the ways families are involved in advisory committees, task forces and work groups. It is a time-honored method used by States to address tasks in public health, so it is not surprising that advisory committees offered familiar opportunities to involve families.

99% of MCH Programs indicate family participation on advisory committees

Chart 6. Percentage of Advisory Committees in which Families Participate (n= 48)

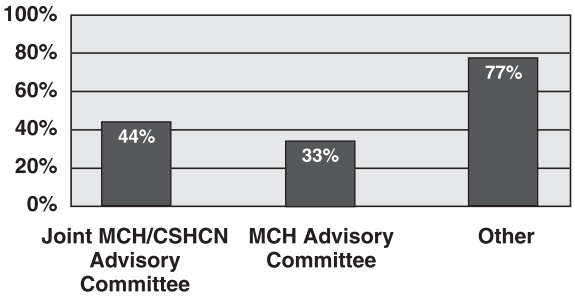


As Chart 6 indicates, State MCH Programs said that families were involved in a few committees (50%); 25% said that families were involved in about half of their committees, only a small difference from the 23% who said that there was involvement in most committees. Only one State said that families were not involved in any committees.

Types of MCH Committees in which Families are Involved

States were asked to indicate the kinds of committees, task forces, or work groups families were involved with and could check more than one.

Chart 7. Types of MCH Committees/Task Forces/Groups in which Families are Involved (n=48)

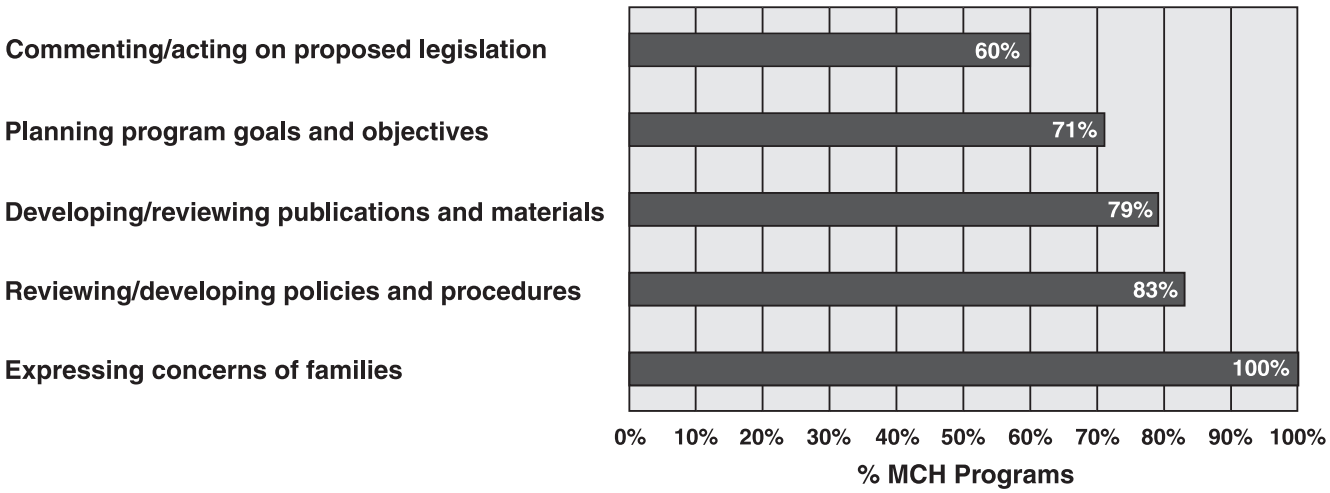


As can be seen in Chart 7, almost 45% of respondents indicated that they had a joint MCH/CSHCN committee, while about 33% had an MCH committee. Not surprisingly, most MCH Programs (77%) said families were involved with various "other committees." There was a wide range of committees mentioned by States: Healthy Mothers Healthy Babies Coalitions, adolescent advisory programs, abstinence-only education programs, child fatality reviews, newborn screening committees, SIDS, perinatal care, child safety, school-based health centers, and lead prevention committees. It should also be noted that in other parts of the interviews it was not uncommon for States to identify additional committees.

Ways in Which Families Contribute

MCH Programs were asked about five areas families might contribute to as advisory committee participants.

Chart 8. Contributions of Families to Advisory Committees (n=48)



We have involved families, including WIC and high-risk pregnant women, eliciting their assistance to advocate for services that benefitted them.

As Chart 8 depicts, all respondents to this question agreed that expressing concerns of families was a key contribution (100%). Not far behind were reviewing or developing polices and procedures (83%), developing or reviewing publications and materials (79%) and planning program goals and objectives (71%). Commenting or acting on proposed legislation was noted least frequently (60%), although that may have been a topic addressed less frequently or may have occurred without the knowledge of the respondent.

Recruitment

Strategies and Outreach to Involve Family Members

MCH Programs were asked how they recruited family members to participate. Their responses indicated a mix of general and specific strategies as well as frustration with some strategies and success with others. Also asked was information about any specific outreach to underrepresented or underserved populations. Fifty respondents offered their thoughts in open-ended comments, indicating both the importance of the effort and sometimes the frustration with achieving it.

We do not involve families. We have an appointed staff person who is a voice for families.

One Program noted that a few parents are depended upon for a lot of input. Another commented that their State is only allowed to form committees mandated by the legislature or some other funding source, thus limiting their ability to involve others.

You have to be willing to commit to it!

Many respondents noted the importance of involving diverse participants, particularly those who are reflective of users of specific MCH Programs. An interesting comment made by one Program was that these days nearly everyone is working, including those on welfare-to-work programs - "Everyone's time is valuable and people expect to be treated in certain ways."

MCH Suggestions for Initial Outreach and On-Going Family Involvement

Communication and Outreach

- Regular communication seems to be successful in retaining families' involvement.
- It's helpful to have a "critical mass" of parents to support each other. It has also been helpful to have a good portion of the committee be parents, not just a few.
- Basically, go out and knock on doors to get recommendations.
- Allow alternative methods of participation – one parent on an advisory group participates by e-mail.
- Encourage parent involvement in planning and foreseeing barriers that may limit participation.
- Use your web site to seek applications, define roles and responsibilities, and send mailings out to families and groups.
- Don't give up – continually look for parents to participate in various groups.
- Build stronger alliances with Early Intervention and CSHCN.
- Encourage parents and families to participate at public forums, family education in-services, public information sessions and ask community partners for names.
- Encourage families' continued support by letting them know how information that they and other parents provide is used.

It is often the parent consultants who provide outreach to parents. There are specific skill sets; it is almost like posting a job specification although we try not to make it so demanding that the people we want to hear from are unable to meet the standards. We've learned to be pretty structured rather than just grabbing any parent who walks by. We do have a lot of diversity and look for multiple languages when we can.

Meeting Specifics

- Use families' time well. Make it meaningful.
- Maximize families' time – plan meetings at times when they may be coming for other meetings or events.
- Be flexible and accommodating, consider non-traditional hours – such as evenings or weekends – offer nighttime activities for different programs, and provide childcare during meetings.
- Work to make sure that meetings are well prepared and organized so it's worth participants' time to come.
- Help with transportation and travel.
- Offer refreshments or a meal at meetings, especially if they are in the evening.
- Move meetings around to various locations to allow for people in different areas to attend. Also, ensure that all meetings are held in accessible locations to accommodate disabilities.
- When possible, allow for flexible scheduling, for example, "The Healthy Mothers Healthy Babies Coalition can schedule meetings whenever they want."

continued

Instead of utilizing families on committees (or in other capacities) at a state office level, develop a structure with the regions. Create family advisory groups of 10-12 members who meet once or twice a year to address issues that are more local or direct in nature, rather than policies that may not have a direct impact on families and may not address their priorities.

Financing

- Offer general financial assistance – pay their way for travel, childcare, and honoraria.
- Use Title V funds creatively because their funding is flexible and less restrictive. It can pay for out of town travel, offer parking and refreshments, etc.
- Work to identify all resources for stipends.
- Find creative payment sources, for example, "Our Healthy Start offers Wal-Mart gift certificates, which are donated."
- Make meetings and activities financially accessible – "We were able to directly pay for the cost of a hotel room using a state department credit card so that families could attend the MCH Advisory Committee meeting and not incur any cost."

continued

States noted many basic strategies for outreach to families such as the use of fliers, notices, and word of mouth. Some felt that putting family outreach on staff agendas and making it a priority was important. Staff such as home visiting nurses could be particularly useful. Personally inviting families was offered as an effective approach. Using the service delivery system effectively – clinics and other community programs – were noted by many, as were using local partners in the community such as local health departments, advocacy groups and other community-based organizations. One State said they ask local health departments to "nominate parents." Contracted agencies were mentioned by a number of States, with some making parent outreach and involvement part of the contract. A State that employs parents said that outreach to involve families is part of the job description. Several States emphasized the importance of involving families from diverse cultural and economic backgrounds, with one saying they build on existing relationships with Native American tribes to involve families. Finally, one State suggested asking families who are already involved for names of others.

Obstacles to Involving Families

MCH Programs were asked about obstacles they encountered in involving family members in committees or task forces on several dimensions.

Chart 9. Obstacles to Involving Families in Advisory Committees, Task Forces and Groups (n=50)

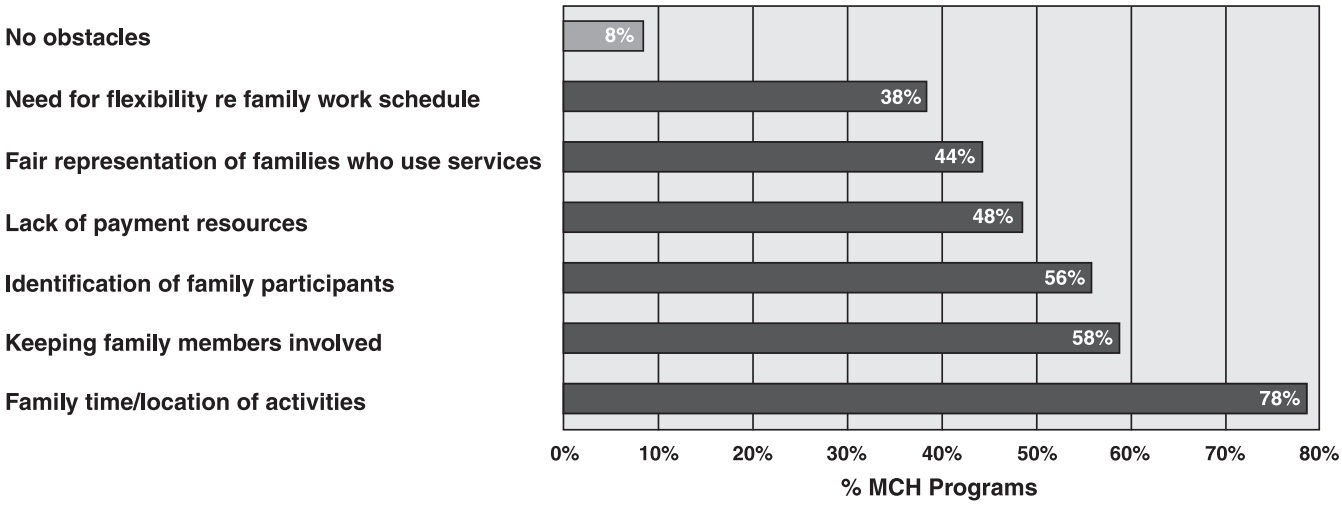


Chart 9 indicates the responses of MCH Programs. Family time constraints or the location of the activities was noted most often (78%). Other difficulties were clustered between 38% and 58% percent. The flexibility needed for families' or staff's schedules was indicated by 38% of respondents; fair representation of families who use services was noted by 44% and lack of resources for paying family participants (or reimbursing for expenses) by 48% percent. Identification of family participants was noted by 56% and keeping family members involved was noted by 58% of respondents. Finally, it should be noted that 8% of MCH Programs said there were no obstacles to involving families.

FAMILY INVOLVEMENT IN ADDRESSING STATE PERFORMANCE MEASURES

State Performance Measures (SPMs)

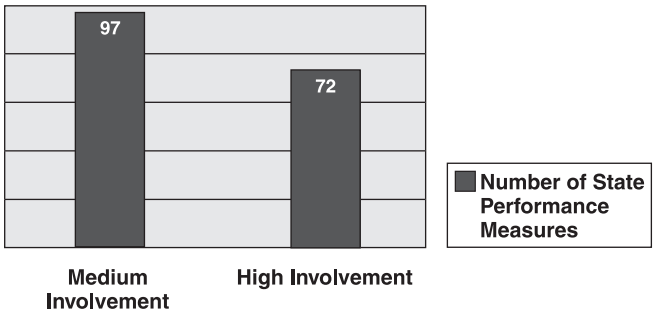
80% of MCH Programs said that families are involved with State Performance Measures

In addition to the National Performance Measures that States are asked to report on in their Title V Block Grant Reports, States also collect data on seven to ten measures of their own choosing – State Performance Measures (previously called State Negotiated Measures). These measures address state needs and at least one should address children with special health care needs. The Maternal and Child Health Bureau defines criteria and must approve the measures, which largely remain the same for several years unless a State requests a change. Although the measures States have developed are often similar, such as reducing childhood overweight or ensuring access to dental care, they are unique and are not comparable across States. However, the measures can be quantified generally by one or more of twenty-six "key words," which is done on the Title V Information System (TVIS). The number has recently been increased to thirty-five key words. States themselves select measures with significance to their populations and spend considerable effort to address them. Family involvement occurs in many of these State Performance Measures.

Degree of Family Involvement

MCH Programs were asked to indicate in which of their SPMs families were involved and whether that involvement was low, medium or high. Presented below are only those measures for which States said family involvement was medium or high.

Chart 10. Family Involvement with State Performance Measures.[7] (n= 49)



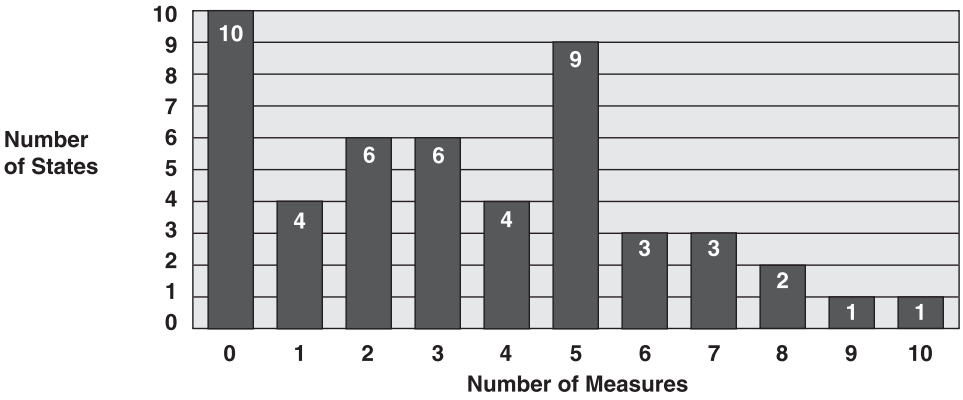
Keyword Categories for Measures with Family Involvement

As mentioned, MCHB's Title V Information System assigns each measure to a "key word" category. The most frequent categories for MCH State Performance Measures in which families were involved were:

- Access to Health Care
- Morbidity/Mortality (Sudden Infant Death Syndrome – SIDS – is included here)
- Primary/Preventative Health Care
- Health Screening

[7] At the time these interviews were conducted it was only possible to estimate the overall number of measures for each State — 7-10 measures times 51 = 357 - 510 measures. States were permitted to drop or change measures and there was no mechanism to reflect this on the TVIS website.

Chart 11. Number of State Performance Measures in which Families were Involved, per Program (n=49)



As indicated in Chart 11, most States mentioned a number of measures in which families were involved, from one measure (4 States) to ten measures (1 State). Ten States reported no family involvement. (One respondent, after considering the response said, "We could have done better.") This was a complex question; some respondents did not feel they were familiar with all the activities of the SPM or ways families were involved. The amount of involvement may in fact be greater. Details about the kinds of family participation might be better sought from sources closer to the activity.

Examples of Family Roles:

- The youth partnership program offered ideas about marketing MCH and SCHIP and served on panels for the legislature.
- Families and teens are involved in developing county adolescent health plans.
- Families were involved in public awareness and access.
- Parents were involved in the media campaign.
- Parents produced parenting newsletters through the child abuse program.
- Parents reviewed manuals and gathered information from parents, including foster parents.
- Adolescents participate on the youth tobacco advisory committee.
- Families pressured schools for tobacco intervention to prevent or reduce usage.
- Families and teens contributed significantly to the State adolescent health plan. Mental health is a key component.
- Families are involved through WIC, using Bright Futures physical activities recommendations.
- Parents are involved in a Fetal Alcohol Syndrome Group.
- People who have gotten out of domestic violence are advisors to the initiative.
- Eleven kids are appointed by the Governor to advise on all youth issues.
- Families help develop educational materials and telephone satisfaction survey for unintended pregnancy and smoking cessation campaigns.

All our performance measures across the MCH perspective were developed with as much community input as we could manage. (Families – high involvement)

Lead Poisoning advocacy is driven by parents. They work on the monitoring of performance and on quality assurance.

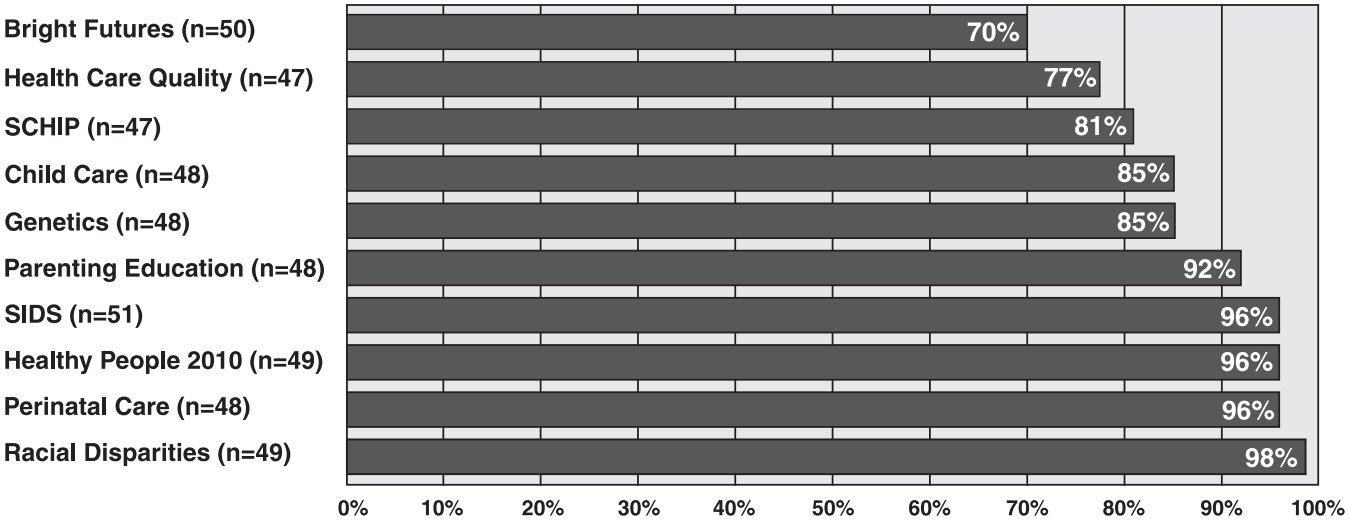
Fathers helped design the Fatherhood Campaign Resource Center and are often the best referrals.

FAMILY INVOLVEMENT IN INITIATIVES TO IMPROVE MATERNAL AND CHILD HEALTH

All States address a number of initiatives with the broad goal of "improving maternal and child health." These initiatives are encouraged by HRSA and the Maternal and Child Health Bureau, and many are traditional public health goals. State MCH Programs are typically located within large state agencies, often a Health Department, which are organized in a variety of ways and whose responsibilities vary from department to department. For this reason, we asked States first whether their MCH Program addressed the initiative, and secondly, whether families were involved. We also asked for any comments they wished to share about the initiative or families' involvement. This proved a very fruitful set of questions and offered interesting examples of ways families were involved although not all States offered additional comments.

100% of MCH Programs report that families are involved in Initiatives to Improve MCH

Chart 12. Percentage of MCH Programs Addressing Special Initiatives to Improve Maternal and Child Health



As can be seen in Chart 12, initiatives such as racial disparities, perinatal care, Healthy People 2010, SIDS, and parenting education were addressed by over ninety percent of MCH Programs. Bright Futures was least likely to be addressed by MCH Programs at seventy percent. The remaining topics – child care, health care quality, genetics, and SCHIP ranged between 75% and 85%.

continued

Chart 13. Percentage of MCH Programs Reporting Family Involvement in Programs that Address Special MCH Initiatives

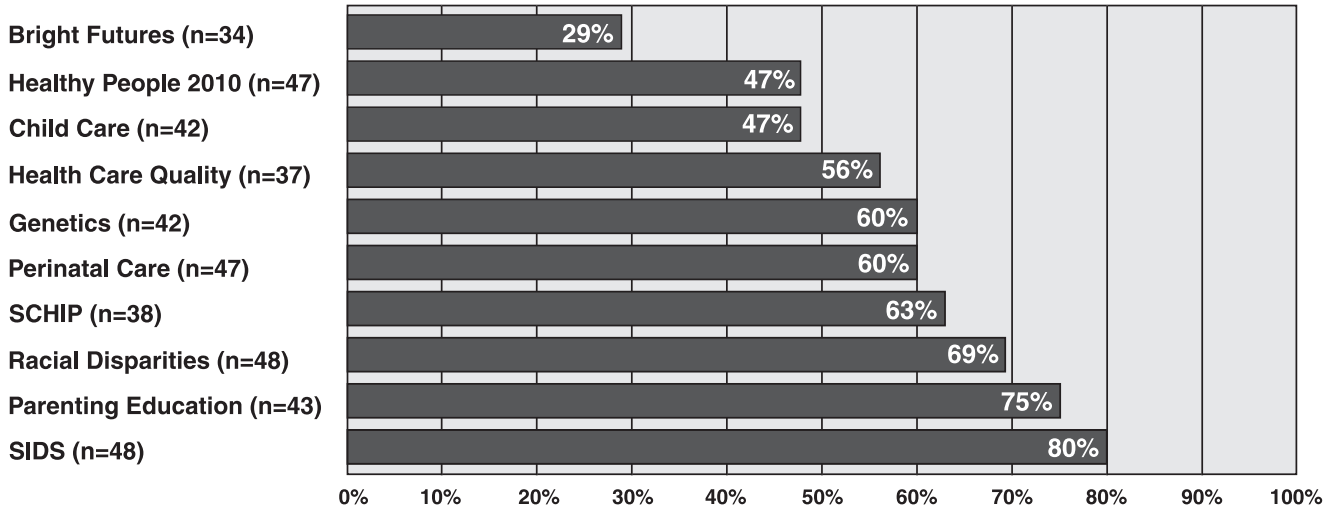


Chart 13 considers only MCH Programs that said they addressed these initiatives and asked whether families were involved. Family members were most apt to be involved in SIDS (80%), parenting education (75%), and racial disparities (69%). Family members were involved to a moderate degree in the following initiatives – SCHIP (63%); perinatal care (60%); genetics (60%); health care quality (56%); child care (47%); Healthy People 2010 (47%). Family members were least likely to be involved with Bright Futures (29%).

continued

Examples of Ways Family Members are Involved in Special MCH Initiatives

Bright Futures
- Families are involved through the Youth Health Initiative.
- Each community uses Bright Futures differently and there is a parent on the workgroup.

Child Care
- "Friends of the Family" provides parenting support to young parents at risk.
- Parents participate in the State Healthy Child Care program and serve on the advisory group.

Genetics
- Families are part of the Genetics and Newborn Hearing Screening Committees.
- The Genetics Privacy and Research Task Force has parent/consumer involvement.
- Parents participate through panels and presentations.

Health Care Quality
- Consumers are part of a State-level coalition.

Healthy People 2010
- Each priority area has consumer/family participants.
- Through a community process we develop our State goals – it's a citizen-based process.

Parenting Education
- Contractors are required to get consumer input on local councils.
- We contract with Parent Line to provide information to parents. We also did a Parenting Calendar.
- Packets and materials for families are reviewed by families. Families also design the outreach plan.
- Home visiting contracts are required to have families on an advisory committee.
- Our Fatherhood Campaign Resource Centers involve fathers.
- Families from tribal communities in rural areas and African-American, Latino, and Southeast Asian families from urban communities plan and conduct an annual family gathering.

Perinatal Care

- The contractor meets on the local level with families and providers.
- Perinatal Councils involve parents.
- Families were involved in the planning and presentations at the Perinatal Summit.

Racial Disparities

- We have a [Robert Wood Johnson] Turning Point grant. Lots of families are involved. They review and help with surveys.
- We have a Resource Mother working with us to develop presentations to the black community.
- Racial disparities activities are infused in all programs and have consumer advisory groups.
- Our Multicultural Health Task Force and seventeen focus groups all include families.

SCHIP

- Consumer liaisons provide outreach to increase enrollment.

SIDS

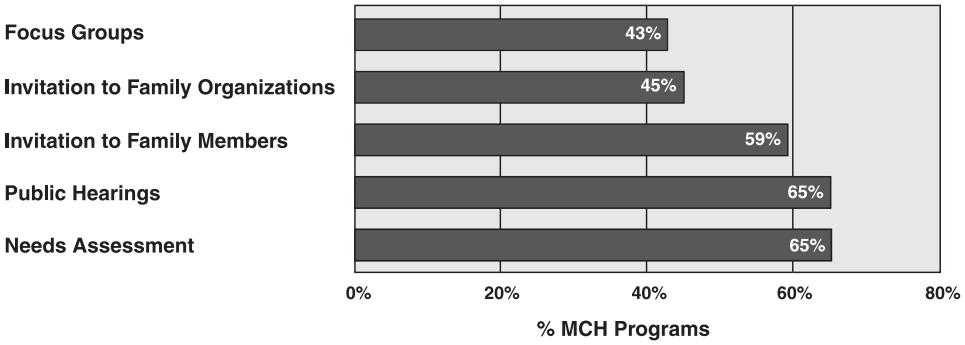
- Parents have a strong voice.
- Families made presentations to the Governor on infant mortality and used SIDS' statistics.
- We started a children's injury prevention coalition. Families provide input on Back-to-Sleep and Co-sleeping.
- A Parent Representative is available to speak with new SIDS parents.
- Parents planned the Memory Walk and assist with literature.

FAMILY INVOLVEMENT IN THE BLOCK GRANT PROCESS

MCH Programs were asked to indicate the ways families or family organizations were involved with their Block Grant application process. Title V Block Grant Reports and Applications are due in mid-July each year, though States are engaged in the efforts and their accounting throughout the year.

100% of respondents reported that families are involved with Title V Block Grant process

Chart 14. Percentage of MCH Programs Reporting Family Participation in Block Grant Process (n=49)



While States had long been required to submit reports to MCHB, in the mid-90's, due to increased emphasis on accountability, significant changes in the requirements were made. Not only did the reporting become uniform, but National Performance Measures were added so that it became possible to look at issues and progress across States. At the time these interviews were conducted, States were still to some degree mastering the new requirements and formats.

All respondents to this question said families were involved. States indicated that they solicited input from families (59%) as well as from family organizations (45%) in a variety of ways. The data indicate that many States saw the importance of involving families in Needs Assessments (65%), not at that time required by MCHB. Making the Block Grant public was a requirement; and many States said they did it at public hearings (65%) and/or in focus groups (43%). However, some indicated that public hearings were a less satisfying method because they were too impersonal, and a number of States noted low turn-out for such hearings.

Twenty-four States indicated they had invited a parent or family member to their own review. Whether this was someone employed by their Program or acting in an advisory capacity was not noted.

Benefits and Difficulties

Many States saw the potential benefits of including families in MCH Programs, with some saying that involvement resulted in families becoming aware of the many programs and initiatives the MCH Program carries out. However, States listed a litany of difficulties to involving families, most emphasizing that the Block Grant is too removed from families' experience and too complex, lengthy, bureaucratic, and even "boring" for readability by families. Given that many States expressed difficulty, it may be significant that 100% had involved families – a federal requirement.

Nonetheless, others recognized the value in involving families and some had figured out more family-friendly methods, with some States noting the value of specifically preparing parents for the Block Grants.

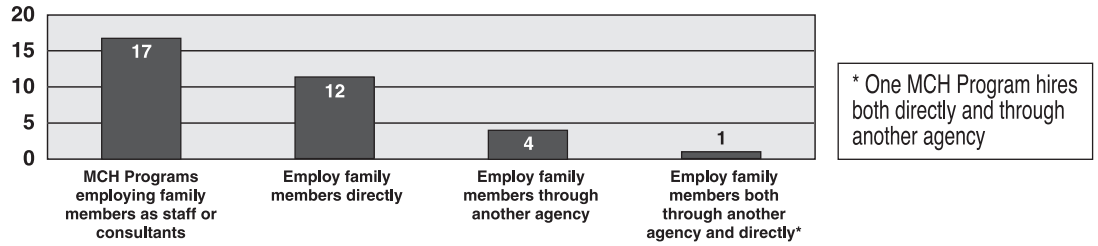
It has opened MCH to the benefit of having families review the Block Grant because family members who come to the review have read the document and question certain aspects of it – this has made us more family-oriented.

Families don't help develop the grant, but we publish a highly distilled version that people can read and understand and can use in forums.

FAMILY MEMBERS EMPLOYED BY MCH PROGRAMS

36% of MCH Programs employ family members as staff or consultants.

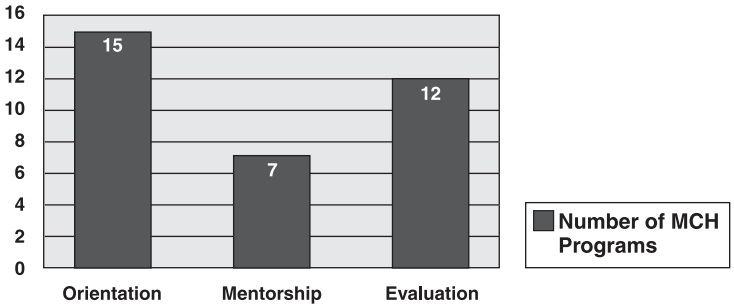
Chart 15. Number of MCH Programs Employing Family Members as Staff or Consultants (n=50)



As Chart 15 portrays, seventeen MCH Programs employ family members, most often parents, as staff or consultants. Twelve hire family members directly; four do so through another agency, and one does both.

The difference between the terms "staff" or "consultants" appeared somewhat artificial. Programs sometimes involved families as consultants for ease of hiring or to circumvent State requirements that families might be unable to meet. In other cases families were hired through another agency, often a parent organization, to ensure that the family employee had ready access to a "family rich" environment with information about current family issues and resources. What the positions were titled or what tasks were associated with the positions often seemed very similar, regardless of the designation.

Chart 16: Assistance and Feedback to Family Members Employed as Staff or Consultants (n=50)



As Chart 16 indicates, fifteen programs provide families with some form of orientation, twelve evaluate families' work, and only seven programs provide some form of mentorship.

Employing family members is a very good thing to do, but do not enter into it lightly or underestimate the expenses. It takes dedicated staff time to do it right. Mentoring – parent to parent, as well as staff to parent mentoring – takes time and effort to work out. Sometimes it doesn't work out. This is, by design, a higher risk effort since you are often starting with people who are not familiar or skilled or necessarily comfortable with the kind or organizations we are asking them to get involved with. Often it works well, but from time to time it doesn't.

Family Members Employed as Staff

Respondents noted that nine States employed families directly; two did so through another agency. MCH Programs indicated that most worked from the State office, with only one each at a county, community, or home office. The job titles for staff were noted as: Family Advocate, Family Consultant, Family Specialist, Parent Coordinator, Resource Parent, and Family and Community Involvement Coordinator.

About half of the Programs said the family members work full time.

Chart 17. Components of Family Staffs' Positions (n=11)

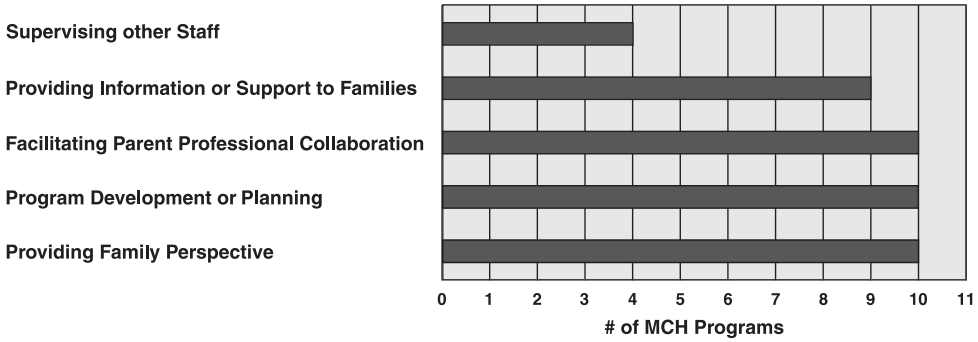
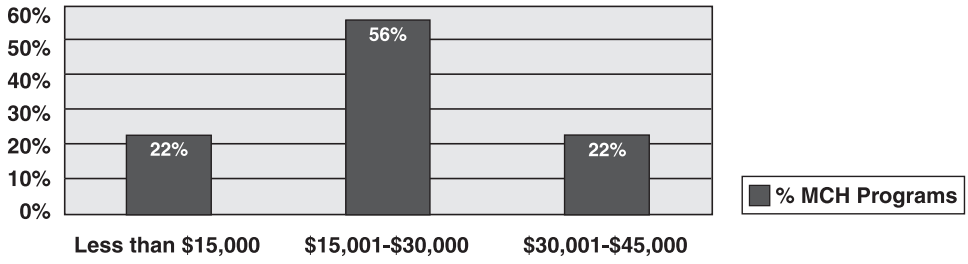


Chart 17 shows that for MCH Programs employing family members, four of the roles asked about in the interviews seemed highly consistent with what States said families do – providing a family perspective (10), involvement with program development or planning (10), facilitating parent-professional collaboration (10), and providing information or support to other families (9). Only supervising other staff was lower (4), likely reflecting the fact that in many States there are no other family members to supervise and that these are newer positions.

Chart 18. Salaries of Family Members Employed as Staff (n=9)



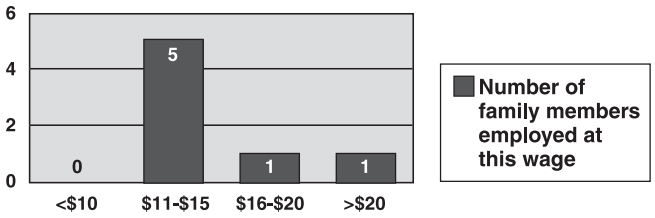
As indicated in Chart 18, salaries for family members employed as staff ranged from less than $15,000 (22%), to between $30,000 and $45,000 (22%), with most in the middle range receiving between $15,000 and $30,000 (56%). As already noted, a number of family employees were employed less than full time; States were asked to give full time equivalents for salary figures.

The Parent Consultant Program is the vehicle we use to pay, support, train, and develop parents to be involved in policy, quality assurance, and outreach. We've had about 35 parents over the last ten years...It started on the CSHCN side...now we assign parents to immunization, lead screening, WIC, early intervention, genetics, and special needs.

Family Members Employed as Consultants

Seven MCH Programs indicated that they hire family members as consultants directly, while four said they do so through another agency. Those employed as consultants had the following job titles: Community Advisor, Parent Consultant, SIDS consultant, communication specialist, junior consultant and senior consultant (based on experience).

Chart 19: Hourly Wages of Family Members Employed as Consultants (n=7)



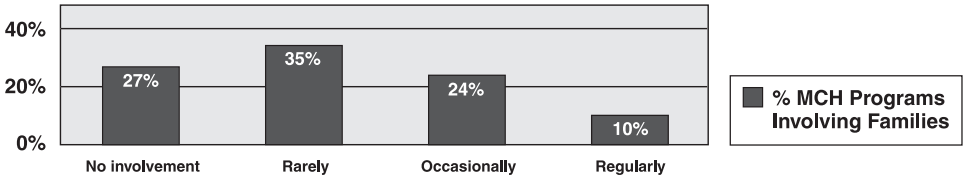
Salaries for consultants were noted as follows: none below $10 an hour; five received $11 - $15 per hour; one received $16 - $20 per hour; and one more than $20 per hour.

FAMILY INVOLVEMENT WITH IN-SERVICE TRAINING

MCH Programs were asked about the frequency of families' participation in in-service trainings. It was first necessary to determine how many programs held such in-service opportunities for their staff.

39% of MCH Programs involve Families in in-service training. (Of 51 programs responding, 48 hold in-service trainings. Of these 48, 19 programs (39%) involve families.)

Chart 20. Percentage of MCH Programs Involving Families in In-Service Training (n=51)



We include a parent in our staff training on infant and child death. This was a parent who had lost a child and helped train the staff in public health.

Twenty-five MCH Programs said that they regularly hold in-service trainings, while 23 said they do so occasionally or rarely. Of the 48 programs, 19 (39%) said they involve families. Five programs said they regularly involve families (10%), while 30 said they occasionally or rarely involve families (59%). (It is possible that responses to this question were related to those Programs that had families on staff.)

Comments And Suggestions About Employing Family Members – 21 MCH Programs

Compensation/Civil Service

- If you are able to pay family members for their travel, be very clear about what is allowable and what you'll pay for.
- We are bound by the state civil service rules. We have eligibility lists and can only hire from those.
- Funding is an obstacle! Parents need to fit into the State's merit system.
- The only way parents can become employed in our State is through another agency.
- If your system is inflexible, go outside the system through another agency. It helps the family member do their job better.
- With current budget issues, hiring anyone is a challenge.

Job Description

- Clearly define expectations. Prior to participation make sure folks are knowledgeable and up to date about what you are trying to accomplish as a whole. Families feel much better about their participation, and it is much more beneficial.
- It would be helpful to get more information from states that are using family members as paid staff to find out the strategies their Human Resources Departments use to hire someone with a specific skill. It would also be helpful to have copies of job descriptions for positions held by families.
- When we brought a parent on it was for CSHCN. I would encourage people to think broader – think Title V in general.

Orientation/Mentoring/Support

- We need to be supportive and nurture family members so they can rejoin the working world. Make sure the training they receive is adequate and appropriate.
- Connect to parent organizations to help support family members and for access to other families.

continued

Part-time/Full-time

- People need to make the commitment to bring someone on full time. When you have someone part - time it's too easy to either overburden that person, or have others undervalue the position.
- There are two sides; "I'm here because I want to be, I'm volunteering my time" or "I'm sharing my expertise as a parent and expect to be paid just as a professional is." You need to respect both opinions, but you do need to have funding available to have that option open.
- Parents who are employed should have substantive involvement in MCH activities to demonstrate their skills and for others to recognize how to use them and their expertise.

Additional

- If we were to do it all over again, orientation would be better, roles would be developed, we would utilize mentors from other states and we would have a better support system in place.
- Establish the position in such a way that the person does not slide into an employee role vs. a family advocate or family representative mode.
- Define parameters of the role to emphasize the value a family representative can bring, yet be able to function in a state system. The parameters given to state employees can often hinder the efforts of family advocates.
- Funding.
- Systems barriers need to be addressed.
- Resolve issues about job qualifications. Agency requirements of a college degree don't always match the qualifications of family consultants or staff. The hiring system needs to be flexible.
- It's important to have a living salary in order to retain family members on staff. This means that salary and job qualifications need to be negotiated as the position is being developed.
- There are retention issues in state agencies when family members are hired. When family members who have worked in an advocacy role are hired by an agency, their roles and responsibilities change – advocacy efforts are not supported within the state agency.

SUPPORT PROVIDED TO FAMILY ORGANIZATIONS AND FAMILIES

SUPPORT FOR FAMILY ORGANIZATIONS

MCH programs were asked to indicate the kinds of support they offered to *families* (as opposed to family organizations) who participate in program and policy activities with them. In a related but different question State MCH Programs were asked about the support they provide to *family organizations*.

71% of MCH Programs offer support to family organizations.

Chart 21. Percentage of MCH Programs Providing Support to Family Organizations (n=49)

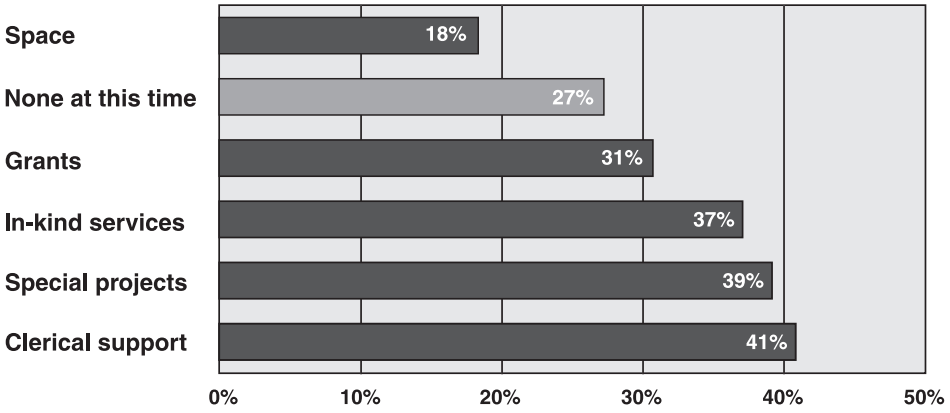


Chart 21 depicts the kinds of supports MCH Programs offer to family organizations. Forty-one percent said they offer such things as clerical support, for instance for mailings. Other supports were: assistance with special projects and in-kind services (39%) and (37%) respectively; grants (31%); space – such as space for meetings (18%). Twenty percent of programs indicated other kinds of support, such as food for meetings.

Of the 39 MCH programs responding to this question, 28% indicated a formal relationship with *Family Voices*; 28% indicated an informal relationship. Nineteen States mentioned relationships with SIDS groups, 11 with LaLeche League, and six with the PTA. Twenty States referred to other family or consumer organizations, most state-specific, such as: foster parents, gay and lesbian parenting, genetic conditions such as sickle cell, family child care providers, home birth program, and a family group concerned with children's Internet access.

Here we also inquired about both formal and informal relationships States had with family organizations. On the questionnaire itself were listed, as examples, *Family Voices*, PTA, LaLeche League, SIDS, and parents of teens. One respondent said it would be helpful to have the kind of formal relationship for MCH that CSHCN has with *Family Voices*.

States mentioned a variety of other organizations and relationships.

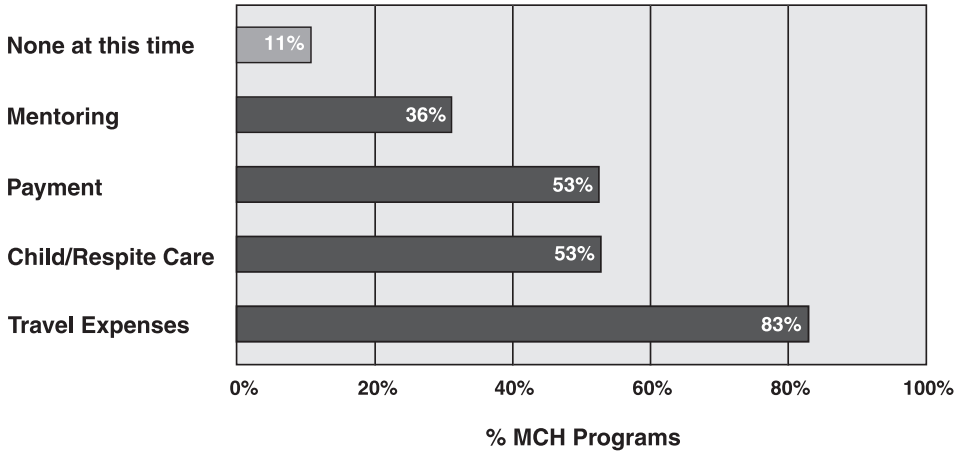
One of the counties was doing a needs assessment that we paid for. They heavily blanketed newspapers and through PTAs, asking for involvement and made a point of stressing that special populations were welcome.

- *We provide a staff person to participate in meetings. – SIDS*
- *We assist with educational information, clerical assistance, material costs, and meeting space. – SIDS*
- *We work with La Leche League primarily through our WIC Program.*
- *Our nurse midwife refers to them and calls on their breastfeeding consultants. – La Leche League*
- *We make referrals to organizations through our MCH contracts.*
- *We work with them on adolescent health – drivers' license issues, injury, etc. – PTA*
- *Through grants we provide peer-to-peer mentoring for teens across the city.*
- *We invite each other to conferences and use them as keynote speakers. – Family Voices*
- *A parent organization co-sponsors Beautiful Babies.*
- *We bring in community members for the teen coalition.*

SUPPORT FOR FAMILIES

94% of MCH Programs offer support to families who participate in program and policy activities.

Chart 22. Percentage of MCH Programs Providing Support to Family Participants (n=47)



As Chart 22 indicates, the support most likely to be offered to families is reimbursement related to travel (83%). Child care or respite care and some form of stipend of payment for time were each offered by 53% of programs. Least likely to be given was mentoring (36%). Eleven percent of programs said they offer no support at this time.

States seemed quite aware of the need to provide support to families involved in program and policy areas and most do so in varying degrees. While many, of course, commented on the lack of resources and the need to obtain them, still others said it was a matter of making it a priority.

Also of note, 30% of programs mentioned other kinds of support such as meals, a per diem if lunch is not provided, or accommodations. One State mentioned that they provide community scholarships for conferences such as March of Dimes Conferences. Another noted that they provide substantial funds to Family Resource Centers that assist families.

STRATEGIES FOR THE INVOLVEMENT OF UNDERSERVED POPULATIONS

State MCH Programs were asked to add any comments not already mentioned about their experiences and ideas on gathering input from underrepresented or underserved populations. In open-ended responses, 26 gave suggestions, two asked for assistance, and eight said they used no special strategies. First it should be noted that reaching out to and meaningfully involving families from diverse populations was threaded throughout responses to the interview questions. MCH Programs were very aware of the need for this. While some seemed satisfied with their efforts, others asked for help and ideas. Many commented on the importance of this as an on-going, and often hard-to-achieve, goal. Comments fell largely in four areas - thinking about this in the context of overall planning (not as a separate, one-time event), use of Minority Health Offices, communication with families, and strategies involving community connections.

We use the toll-free Mom and Baby Healthline. There are Spanish-speaking, Asian and Pacific Islander language operators... they recruit.

Background Thinking and Pointers

- Build in strategies to obtain input from diverse populations.
- Use or develop collaborative incentives to obtain input.
- Customer satisfaction is critical, so make it a priority to obtain feedback!
- Program planning and the development of educational materials.
- Reach out to smaller as well as larger groups representing diverse populations in your State.

Minority Health Offices

- Work with and use the resources of your Minority Health Office ("MH staff holds community meetings").
- Create joint efforts with Minority Health to seek out information and address needs.
- Take advantage of on-going as well as topical special initiatives (Multicultural Task Force, etc).
- Staff is typically very diverse and works to ensure diversity in all groups.

continued

- *We met in Vietnamese neighborhoods to get input from the Vietnamese population.*
- *We have a very comprehensive web page that includes sections in Spanish.*
- *If the parent consultants we have at the moment speak Spanish and Russian and the latest population that arrives speaks Chinese – there is an issue! We just can't have everyone represented in every program.*
- *We provide printed materials – English, Spanish, Haitian, Russian, Chinese. We also read to them if they can't read in their native language.*
- *Our Parent Consultant Program is quite strongly linked at the department level with the Minority Health Program and has helped a lot with trainings.*
- *We go into the community and look for key people who can open doors to others, in small towns and large cities. We're a very personal state!*

Communication

- Translation activities are essential, including 800 lines with translation services.
- Train staff in languages you expect them to encounter.
- Provide simultaneous translation for immigrant communities.
- Parents you employ can be a "point of access" to dozens of other families.

Community Connections

- Identify and work with community coalitions and groups.
- Minority Health Offices in many States have or can create community connections.
- Community fairs – give out "goodies" as incentives for families to attend and give input.
- Work with local service providers, including contractors to obtain input and participation.
- Work with advocacy or non-profit groups. They're not necessarily from underrepresented groups but are invested in the issues and have connections to them.

FAMILY INVOLVEMENT IN MCH AND CSHCN PROGRAMS, 1992 and 2002

Chart 23. Summary Findings: 1992 & 2002

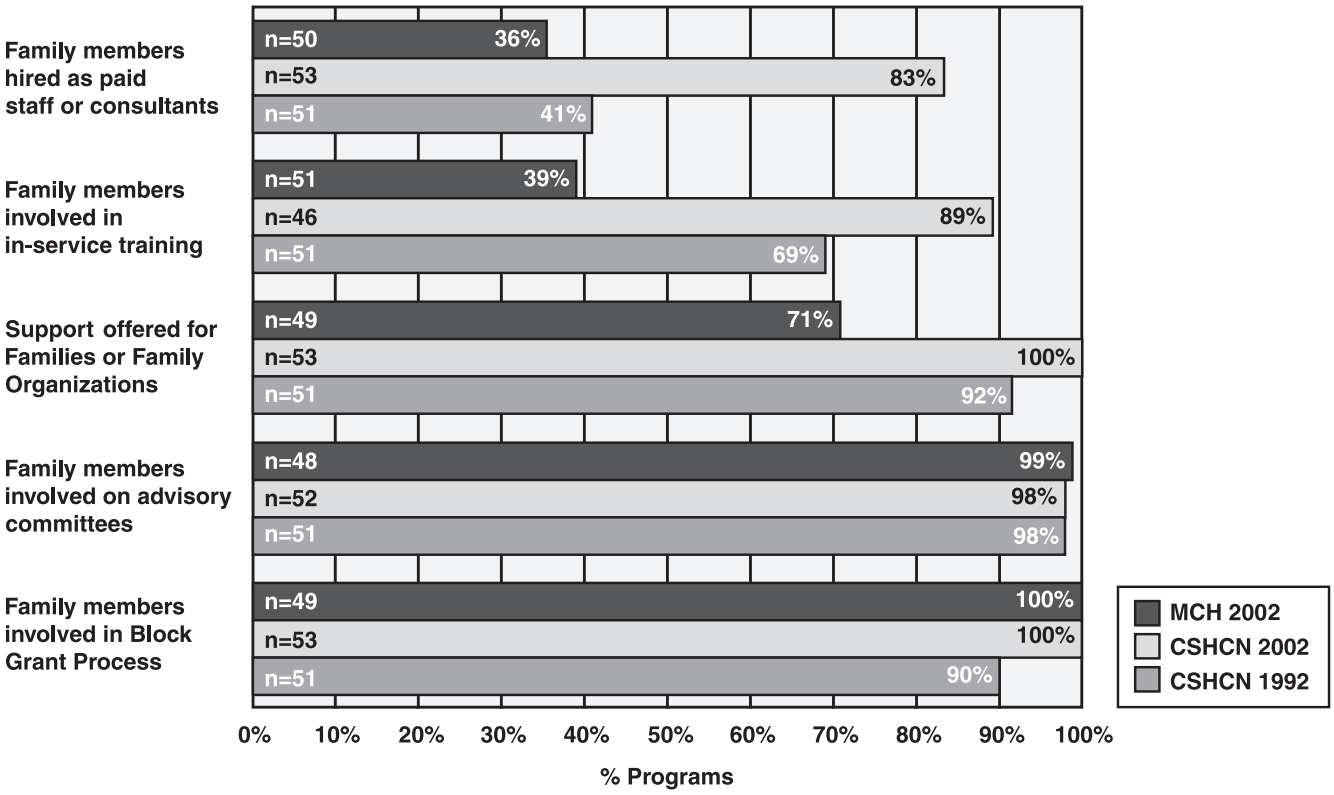


Chart 23 provides a summary of information on family involvement in key areas for MCH 2002, CSHCN 2002, and CSHCN 1992.

In asking about the extent to which family members are employed, the lowest scoring category for any of the three, the figures for MCH 2002 (36%) appear somewhat similar to those for CSHCN in 1992 (41%), while by 2002 the CSHCN figures have doubled, to 83%.

For family involvement with in-service training, MCH 2002 is 39% while CSHCN has increased from 69% in 1992 to nearly 90% in 2002. We do not know if the "involved families" are actually those employed by the MCH or CSHCN Programs.

In the area of support to families or family organizations (a combined question in 1992), support was offered by 92% of CSHCN Programs in 1992 and by 100% in 2002. In 2002 MCH Programs indicated that they provided supports to 71%.

Finally, as can be seen, in areas such as family involvement with the Block Grant process and on advisory committees and task forces, the figures are at or above 90% for all three inquiries.

For CSHCN Programs there has been growth in all areas of family involvement with the exception of advisory committees, already at 98% in 1992. It will be interesting to track the involvement of families in MCH Programs over the next years to see if a similar pattern occurs.

INSIGHTS AND RECOMMENDATIONS

This first report on family involvement, based on interviews with State MCH Programs, indicates that families are involved in varying degrees in every State. Moreover, there is a strong sense among many Programs that family involvement with MCH Programs is a value and a goal, even if not completely achieved. The many ideas, resources, and strategies offer a significant base on which to build.

The following insights and recommendations are drawn from the comments and data supplied by State MCH staff. They are intended to provide guidance to State MCH Programs, MCHB, family leaders, and others on ways to continue to improve family-centered-services and programs through family-professional partnerships.

1. State MCH Programs described a wide array of involvement with families. MCH Programs should be reinforced and acknowledged for their efforts and achievements.

2. MCH Programs by their nature and design offer significant strengths and opportunities at the community level. Communities seem a perfect place to involve a wide range of families. States should be encouraged to create community partnerships with families – and to share their insights, challenges, and successes.

3. Recognition of the diverse cultures served by State MCH Programs came through strongly in the interviews. The many suggestions about respectful strategies and outreach should be shared with others.

4. State Performance Measures and initiatives to improve maternal and child health were areas in which many States indicated varied and interesting ways of involving family members. These should be further explored and expanded upon in the future.

5. States indicated significantly fewer relationships with family organizations. Even when States were involving families in a variety of activities, many did not appear to involve family organizations. States should seek out family organizations in order to make use of the energy, information, networking, outreach, and advocacy these groups often provide.

6. While many specific efforts involving families were described, few States mentioned broad or unifying efforts to bring families together. MCH Programs could consider an approach to create opportunities to "put the child together" by bringing together many diverse organizations and interests for children's health - LaLeche League, Mothers Against Drunk Driving, the PTA, and others. (For example, from the single-condition approach for children with special needs, the language and concepts were broadened to the more global approach for "children with special health care needs.")

7. While only some States indicated that they held regular in-service training, many fewer said they involve families, either as participants or as speakers. This may be related to the fact that relatively few MCH Programs hire family members as staff or consultants who might logically attend such in-service trainings. Nevertheless, States should consider ways to involve family members as informative and motivating speakers for their staff.

8. Many State MCH Programs noted the lack of opportunities to learn from each other in order to share information about best ways to involve families in their Programs – especially around issues such as involving families from varied socio-economic backgrounds and in activities involving prevention. Models for involvement and opportunities for discussion of effective ways to involve families could be showcased and discussed through AMCHP or other avenues. One vehicle might be the *Family Voices* Title V Toolbox, which contains many models and ideas of potential help to MCH Programs. The Toolbox should be expanded and publicized to MCH Programs.

9. The Maternal and Child Health Bureau Strategic Plan calls for family-centered care for all MCH populations. State MCH Programs should be asked to track family involvement in ways similar to those required of CSHCN Programs.

10. Like the CSHCN report in 1992, but unlike that for 2002, there is no logical group of families to contact in States for their experience and views of MCH Programs. This is a significant lack. MCH Programs should form alliances and relationships with families so that there are families who have enough information and experience with their programs to be able to comment thoughtfully about them – as a means to improving care, services, and policies.

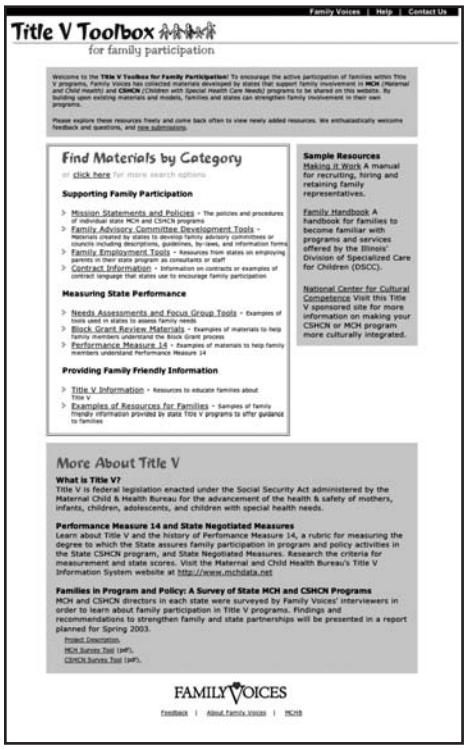
TITLE V TOOLBOX* FOR FAMILY PARTICIPATION:

A Web-Based Repository of State Resources to Support Family/Title V Collaboration

The *Title V Toolbox for Family Participation* provides a central forum for states and families to learn about existing models and methods for involving families in Title V programs. It is also a place where states that have been successful in developing working partnerships with parents can share their expertise to support fledgling efforts in other states. As one family coordinator in a state health department said of this project, "I wish this [resource] had been available to me three years ago when I started."

Types of Toolbox Resources

www.familyvoices.org/toolbox



The *Title V Toolbox* shares resources for supporting family participation, such as:

- Mission statements and policies of individual state MCH and CSHCN programs
- Family advisory committee development tools
- Tools for employing parents as consultants or staff
- Information on contracts or examples of contract language

Resources on measuring state performance, such as:

- Needs assessments and focus group tools
- Block Grant review materials
- Materials to help family members understand Performance Measure 14 (now Form 13)

The *Toolbox* also contains examples of family friendly information developed by states and others such as:

- Resources to educate families about Title V
- Samples of family friendly information to offer guidance to families

General information and useful links are also provided to help families learn more about Title V and ensuring cultural competency.

The *Toolbox* also provides an easy to use mechanism for submitting materials for posting, allowing a continually renewable source of valuable resources.

Finding the Toolbox

The *Title V Toolbox* is located on the *Family Voices* website at www.familyvoices.org/toolbox.
The *Toolbox* is also linked to the *Family Voices* homepage.

Use of the Toolbox to Date

The *Toolbox* was launched in Spring, 2003 and has averaged over 1200 web hits per month.

* Note: this aspect of the FiPPs survey was funded by the Division of Services to Children with Special Health Needs, MCHB.

STATE-BY-STATE TABLES

Table I. Family Involvement in MCH Programs: Overall Benefits to Program

	Family Involvement in Program Activities	Family Involvement Required in Contracts	Benefit to Program L=Low M=Medium H=High						
			Awareness of family issues	Planning for more responsive services	Program Understanding by legislature, public & state	Parent Professional Communication	Availability of Family Members	Coalition for Change	Responsive to Federal Requirements
AK									
AL	Occasional	NO	H	H	M	H	M	H	L
AR	Not Yet Involved	YES	M	L	M/H	M	L	L	L
AZ	Not Yet Involved	YES	H	M	M	M	L	L	L
CA	Not Yet Involved	YES	H	H	M	L	L	H	
CO	Occasional	NO	M	L	L	L	L	L	L
CT	Occasional	YES	H	M	M	M	L	L	M
DC	Most	NO	H	H	M	H	H	H	L
DE	Occasional	YES	H	H		H			
FL	Occasional	YES	M	M	M	M	M		L
GA	Most	YES	M	L	M	H	L	H	H
HI	Occasional	YES	L	H	M	L	H	L	L
IA	Occasional	NO	H	H	M	M	L	L	L
ID	Occasional	NO	H	H	M	M	M	H	M
IL	Occasional	YES	H	H					H
IN	Occasional	NO	M	M	M	M	M	L	L
KS	Occasional	NO	L	L	L	L	L	L	L
KY	Occasional	YES	H	H	H	H	M	M	M
LA	Most	YES	M	M	L	L	M	M	M
MA	Occasional	YES	H	H	L	M/H	M		L
MD	Most	NO	H	H	M	M	M	M	
ME	Occasional	NO	M	M	L	L	M	L	L
MI	Occasional	YES	M	M	H	M	M	H	M
MN	Occasional	NO	M	L	M	L	L	L	L
MO	Most/Occ	YES	M	H	M	M	M	M	M
MS	Most	YES	M	M	H	L	M	M	L
MT	Occasional	YES	M	M	M	L	L	L	M
NC	Most	NOT SURE	H	M	M	M	M	M	M
ND	Occasional	NO	M	L	M	L	L	L	M
NE	Occasional	YES	L	L	L	M	L	L	L
NH	Occasional	YES	H	M	L	L	L	L	NOT SURE
NJ	Occasional	YES	H	M	M	H	M	M	M
NM	Occasional	YES	M/H	M/H	M/H	H	M	M/H	M
NV	Not Yet Involved	NO	L	L	L	L	L	L	L
NY	Most	YES	H	H	H	H	H	M	H
OH			L	H	L	L	M	L	L
OK	Occasional	YES	M	H	M	H	M	M	M
OR	Occasional	YES	M	H	M	M	L	L	L
PA	Not Yet Involved	NO	L	L	L	L	L	L	L
PR	Occasional	NO	M	M	L	M	L	L	M
RI	Most	NO	H	M	H	M	H		H
SC	Not Yet Involved	YES	L	L	L	L	L	L	L
SD	Not Yet Involved	NO	L	L	L	H	L	L	L
TN	Occasional	NO	M	L	L	M	M	L	L
TX	Occasional	NO	M	M	L	M	M	L	L
UT	Not Yet Involved	YES	H	H	M	H	M	M	M
VA	Occasional	NO	M	M	L	M	M	L	M
VI									
VT	Occasional	NO	H	M	L	M	M	M	L
WA	Occasional	YES	M	M	M	M	L	L	L
WV	Most	YES	H	H	M	M	M	H	M
WI	Occasional	NO	H	M	L	M	M	L	M
WY	Occasional	YES	H	H	H	H	M	H	L

Table II. Family Involvement in MCH Programs: Summary Areas

	Involved on Advisory Committees	Involved in In-service Training	Involved in State Performance Measures	Involved in Black Grant Process
AK				
AL	YES	NO	YES	YES
AR	YES	YES	YES	YES
AZ	YES	YES (Rare)	YES	YES
CA	YES	NO	YES	YES
CO	YES	YES	YES	YES
CT	YES	YES (Rare)	YES	YES
DC	YES	YES	YES	YES
DE	YES	YES (Rare)	YES	YES
FL	YES	YES (Rare)	LOW	YES
GA	YES	YES (Rare)	YES	YES
HI	YES	YES	YES	YES
IA	YES	YES (Rare)	YES	YES
ID	YES	NO	YES	YES
IL	YES	NO	LOW	YES
IN	YES	YES (Rare)	YES	YES
KS	YES	YES (Rare)	LOW	YES
KY	YES	NO	YES	YES
LA	YES	YES	YES	YES
MA	YES	YES (Rare)	YES	NO
MD	YES	NO	YES	YES
ME	YES	YES	YES	YES
MI	YES	YES (Rare)	YES	YES
MN	YES	YES (Rare)	YES	YES
MO	YES	YES	YES	YES
MS	YES	YES (Rare)	YES	YES
MT	YES	NO	YES	YES
NC	NO	YES	YES	YES
ND	YES	NO	YES	YES
NE	YES	NO	LOW	YES
NH	YES	YES	YES	NO
NJ	YES	YES	YES	YES
NM	YES	YES	YES	YES
NV	YES	YES	YES	YES
NY		YES	YES	YES
OH		YES	YES	YES
OK	YES	YES	YES	YES
OR	YES	YES		YES
PA	YES	NO	LOW	YES
PR	YES	NO	LOW	YES
RI	YES	YES	YES	YES
SC	NO	NO	LOW	YES
SD	YES	NO	YES	YES
TN	YES	YES	LOW	YES
TX	YES	NO	LOW	YES
UT	YES	YES		YES
VA	YES	NO	YES	YES
VI				
VT	YES	YES	LOW	YES
WA	YES	YES	YES	YES
WI	YES	YES	YES	YES
WV	YES	YES	YES	YES
WY	YES	YES	YES	YES

Table III. Family Participation in MCH Advisory Committees

(x represents States indicating yes)

State	Family Participation	Types of Committees			How Families Contribute					Obstacles to Involvement					
	Most, About Half, A Few, None	A Joint MCH CSHCN	B MCH Adv	C Other	Expressing concerns	Planning program goals/objs	Reviewing policies/ procedures	Reviewing pub. materials	Reaction to composed legislation	I.D. of family participants	Lack of monetary resources	Family time limits	Lack of flexibility	Fair rep's for families	Keeping members involved
AK															
AL	A few	X	X	X	X	X	X	X	X	X		X		X	X
AZ	A few		X		X		X	X	X		X		X	X	X
AR	A few			X	X		X	X	X			X			X
CA	Most		X		X				X	X		X	X	X	
CO	A few		X		X	X	X	X	X	X		X			X
CT	A few			X	X		X	X		X	X	X			
DC	Most	X	X	X	X	X	X	X	X	X	X			X	X
DE	A few			X	X	X		X		X	X	X	X		X
FL	A few			X	X		X	X		X	X	X			X
GA	Most	X	X	X	X	X	X	X	X	X	X	X			X
HI	A few			X	X	X	X	X			X	X	X		X
IA	About half	X		X	X		X	X	X			X		X	
ID	A few			X							X	X			X
IL	About half			X	X		X	X		X					X
IN	About half	X		X	X	X	X	X	X	X		X	X		X
KS	A few			X	X										
KY	About half			X	X	X	X	X	X	X		X	X	X	
LA	Most			X	X	X	X	X		X		X	X		X
MA		X								X				X	X
MD	A few			X	X			X	X						
ME	A few			X	X		X	X	X	X		X	X	X	X
MI	Most		X	X	X	X	X	X				X	X		
MN	A few		X	X	X	X	X	X	X			X		X	X
MO	Most	X		X	X	X	X	X	X		X	X			
MS	Most		X	X	X	X	X	X	X		X	X	X	X	X
MT	A few	X	X	X	X	X	X			X		X	X	X	
NC	About half				X	X	X	X	X	X	X	X		X	
ND	A few	X	X		X	X			X		X	X			X
NE	A few			X	X	X	X	X	X	X		X	X		X
NH	A few			X	X	X	X	X	X						
NJ	About half			X	X			X		X	X	X			
NM	About half	X			X	X	X	X	X	X	X	X	X	X	X
NV	A few	X		X	X	X	X	X	X	X	X				
NY		X			X	X	X	X	X		X	X	X	X	X
OH		X		X						X		X		X	
OK	Most			X	X	X	X	X	X	X	X	X	X	X	X
OR	Most	X		X	X	X	X	X	X		X			X	X
PA	A few			X	X	X	X			X		X			X
PR	A few		X	X	X	X				X	X	X			X
RI	About half			X	X	X	X	X	X	X		X		X	
SC	None				X	X	X								
SD	A few	X			X	X	X	X		X	X	X	X		X
TN	A few		X	X	X	X	X				X	X	X		X
TX	About half		X		X	X	X				X	X		X	
UT	A few	X			X				X	X					X
VA	About half	X		X	X		X	X			X	X		X	
VI															
VT	About half	X			X	X	X	X	X	X		X	X	X	
WA	A few			X	X		X	X							
WV	Most	X	X	X	X	X	X	X	X			X		X	
WI	About half	X			X	X	X	X			X	X	X		
WY	Most	X	X	X	X	X	X	X	X			X			X

Table IV. MCH Initiatives to Improve Maternal and Child Health
X indicates MCH Program Areas
F indicates Family Involvement

	Bright Futures	Health Care Quality	Healthy People 2010	Racial Disparities	SCHIP	SIDS	Perinatal Care	Parenting Education	Child Care	Genetics
AK										
AL	X		X			XF	X		X	
AR	X	X	X	X	XF	XF	XF	XF	XF	XF
AZ		XF	XF	X	XF	XF	XF	XF	X	XF
CA		X	XF	XF		XF	XF	XF		
CO		XF		XF	XF	X	XF		X	X
CT		XF	XF	XF		XF				XF
DC	XF	X	XF	XF	XF	XF	XF	XF	XF	XF
DE	XF	X	X	XF	X	XF	XF	X	X	X
FL	X	XF	X	XF	XF	X	X	XF		
GA		XF	XF	XF	XF	XF	XF	XF	X	XF
HI	X	X	X	XF	X	XF	X	XF	XF	
IA		XF	XF	XF	XF	XF	X	XF	XF	XF
ID		X	X	X	XF	X	X	XF	X	X
IL	X		X	XF		XF	X	X	X	
IN	X	X	XF	X	X	XF	XF		X	XF
KS	X	X	X	XF	XF	XF	X		X	X
KY	X		XF	XF	X	X		XF	X	XF
LA	X	XF	X	XF	XF	XF	XF	XF	XF	X
MA	XF	XF	X	XF	XF	XF	*PILOT			
MD	X	XF	XF	X	X	XF	XF	XF	X	X
ME	X	XF	XF	X	X	XF	XF	XF	XF	XF
MI		XF	XF	XF	XF	XF	XF	XF		XF
MN	X		XF	XF		XF	XF	XF	X	XF
MO	XF	XF	XF	XF	XF	XF	XF	XF	XF	XF
MS	XF	XF	XF	XF	XF	XF	XF	F		XF
MT	X		X	XF	X	XF	X	XF	XF	X
NC	X	XF	XF	XF	XF	XF	X	XF	X	X
ND	X	XF	XF	XF	X	X	X	XF	X	X
NE		X	X	XF		XF	X	XF	X	XF
NH	X	X	X	X	X	XF	X	XF	X	X
NJ	X	XF	X	XF	XF	XF	XF	X	XF	X
NM		XF	X	XF	XF	XF	XF	XF	XF	XF
NV	X			X	XF	X	X	X	X	X
NY	XF	XF	XF	XF	XF	XF	XF	XF	XF	XF
OH	X		X	XF	X	XF	*PILOT			F
OK	XF	XF	XF	XF		XF	XF	XF	XF	XF
OR	X		XF	X	X	X	XF	X	XF	XF
PA		X	XF	XF	XF	XF			XF	X
PR			X		X		X	XF	XF	XF
RI	XF	XF	XF	XF			XF	XF	XF	XF
SC	XF	X	X	X	X	X	X	X	X	X
SD	X		X	X	XF	XF	X	X		X
TN			X	X		XF	X	X	XF	XF
TX	X	XF	X	X	XF	XF	XF	XF		XF
UT		X	X	X	XF	X	X	X	X	
VA	X			XF		XF	XF	XF	X	X
VI										
VT			XF	XF		X	X	XF	X	XF
WA	XF	X	X	XF	XF	XF	XF	XF	XF	
WV	X	X	X	X	X	XF	XF	XF	XF	X
WI	X	X	X	XF	F	XF	XF	XF	X	X
WY						XF	XF	XF		XF

*Pilot - not all questions were asked

Table V. MCH Support for Families and Family Organizations
(X represents States indicating yes)

	Support for Families Who Participate with the MCH Program				Support for Family Organizations that Participate with the MCH Program				
	Child Care / Respite Care	Mentoring	Payment for Time/Services	Travel $$ for Meetings, Conferences	In-kind Services	Space	Clerical Support (newsletters, mailings, etc.)	Special Projects	Grants
AK									
AL			X	X			X	X	
AR				X				X	
AZ			X	X					
CA				X					
CO			X	X	X		X		X
CT	X								
DC	X	X	X	X	X	X	X	X	X
DE							X		
FL			X	X				X	
GA			X	X	X			X	
HI	X			X	X		X	X	X
IA	X		X	X		X	X	X	
ID	X	X		X	X	X	X		X
IL	X	X		X					
IN		X	X	X		X	X	X	X
KS									
KY			X	X					
LA		X	X			X		X	
MA									
MD				X	X				
ME	X			X					
MI	X	X	X	X	X				X
MN	X		X	X	X				X
MO	X	X		X					
MS		X	X	X	X	X	X		X
MT	X		X	X	X		X	X	
NC	X		X	X				X	X
ND				X					
NE	X			X					
NH									
NJ	X			X					
NM	X	X	X	X	X		X	X	X
NV									
NY	X	X	X	X	X		X		
OH									X
OK	X		X	X	X	X	X	X	
OR	X	X	X	X			X	X	
PA	X			X					
PR									
RI	X	X	X	X	X	X	X	X	X
SC	X	X							
SD				X					
TN	X	X		X	X		X	X	X
TX				X			X		
UT									
VA				X					
VI									
VT	X	X	X	X					X
WA			X						
WV	X	X	X	X	X	X	X	X	
WI	X		X	X	X		X	X	X
WY		X	X	X	X		X	X	

MCH QUESTIONAIRE

Families in Programs and Policy: Interviews with State MCH and CSHCN Programs

FAMILY VOICES®

MCH Interview Tool

Family Voices, a national grassroots network of families of children with special health care needs, is collecting information on family participation in program and policy activities using a telephone survey. *Family Voices'* parent leaders will call to interview a staff person from both state Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) programs in each state.

As you answer these questions, please think about:

- Involvement of families/family organizations in program and policy activities – By this we mean family members or groups who advise or assist the Title V program to understand needs and to provide quality care and services for all children and families.
- Our broad definition of what constitutes a family or family organization: one that includes, for example, relatives, guardians, and foster families as well as parents and siblings.
- The particular efforts your program has made to include family members from a diverse range of socio-economic, racial, cultural and ethnic backgrounds.
- Family involvement within your program *during the past 12 months*.
- Your MCH program. Keep in mind that an almost identical set of questions is being asked of the CSHCN program. We are very aware that CSHCN programs have typically had many more years of work with families. A similar set of questions will explore and collect baseline information on MCH program activities with families. Please don't base your answers to this survey on Early Intervention (EI) activities. Information on parent involvement in EI is being collected by another project. Question I-E asks how family involvement in MCH programs has been influenced by EI.

I. Family involvement in your MCH program

A. To what extent are families part of program and policy activities in your program? Families and family organizations are…

___ involved in most of the things we do
___ occasionally involved in what we do
___ not really yet involved in what we do.

Please tell us more about the key ways families and family organizations are involved in your MCH program.

B. Approximately how long have families been involved in your MCH program?
___ 1-5 years ___ 6-10 years ____ over 10 years

C. Does your MCH program specify or require family member involvement in any of the contracts you develop for the provision of services?
yes _____ no _____
If yes, please offer examples.

D. Considering all your MCH activities, please tell us the degree to which family involvement has benefited your program.

Benefit to program	Degree Low	Med	High	Comments
Increased awareness and understanding of family issues and needs				
Improved planning and policies resulting in services more directly responsive to family needs				
Improved understanding of programs by legislature, state officials, and the public				
Increased parent/professional communication and understanding				
Increased availability of family members able to participate in training, public awareness and policy development				
Established base for a strong coalition for change within the program				
Increased responsiveness to Federal requirements				
Other				

E. Please tell us the degree to which family involvement in your MCH activities has been influenced by EI activities in your state.

___Low _____Medium ___High

II. Family involvement in addressing state needs.

A. Please indicate the degree of family involvement in each of your state's Title V State Negotiated Performance Measures (refer to the attached sheet of your state/territory's negotiated measures).

State negotiated measures for [state] Please write in the number of the state negotiated measure you are addressing.	Family Involvement Low	Med	High	Please specify how families are involved.
SP__				
SP__				
SP__				
SP__				
SP__				
SP__				
SP__				
SP__				
SP__				
SP__				

B. Please comment on the following special initiatives to improve maternal and child health.

Initiative	Does your program address this? Yes	No	Are families involved? Yes	No	Comments
Bright Futures					Bright Futures Contact
Health Care Quality					
Healthy People 2010					
Racial Disparities					
S-CHIP					
SIDS					
Perinatal care					
Parenting Education					
Child Care					
Genetics					
Other					

III. Family involvement in advisory committees/taskforces/groups

A. Considering all the committees/task forces/advisory groups in your MCH program, in approximately what percentage of these do families participate?

___ Most ___ About half ___ A few ___ None

B. Please indicate the types of MCH committees/task forces/groups families are involved in (check all that apply)

___ Joint MCH/CSHCN Advisory Committee
___ MCH Advisory Committee
___ Other _____
_____
_____

C. Thinking of all your MCH committees/task forces/groups, please tell us how families contribute (check all that apply).

	Comments
___ Expressing concerns of families	
___ Planning program goals and objectives	
___ Reviewing and/or developing policies and procedures	
___ Developing and/or reviewing publications and materials	
___ Commenting or acting on proposed legislation	
___ Other (please specify)	

D. How do you recruit families to be part of these committees/task forces/groups? How do you insure outreach to special or diverse populations?

E. What difficulties or obstacles to involving family members on committees/task forces have you encountered? (Check all that apply and please indicate by numbers the top three obstacles your program encounters).

___ identification of family participants
___ lack of resources/methods for paying family members for time/expenses
___ family time constraints or location of activities
___ need for flexibility for family staff's work schedule
___ fair representation of families who use services
___ keeping family members involved
___ Other _____
___ None

How have you addressed these issues?

IV. Staff In Service Training

A. How often do you hold in-service trainings for staff?

___ regularly ___ occasionally ___ rarely ___ no in-service trainings

B. How often are family members involved in staff in-service training?

___ regularly ___ occasionally ___ rarely ___ no involvement

You should be half way done with your interview

V. Family involvement in the MCH Block Grant application process

A. Please indicate ways families or family organizations are involved in your Block Grant application process (check all that apply):

Methods of family involvement	Comments
_____ Public Hearings to develop and or review	
_____ Focus groups/meetings for families to develop and or review	
_____ One or more family members invited to develop and or review	
_____ One or more family organizations invited to develop and or review	
_____ Developing needs assessment(s)	
_____ Other (specify)	

B. In 2000 or 2001, did you invite a parent or family member to attend your regional Block Grant Review?
___Yes _____No

C. What benefits have occurred in your program from having families involved in the Block Grant process?

D. What difficulties or obstacles has your program encountered involving families in the Block Grant process?

VI. Support for and relationships with *families and family organizations*.

A. Indicate the kinds of support your MCH program offers to *families* who participate in Title V activities in program and policy (check all that apply) :

___ child care/ respite care
___ mentoring
___ payment for time or services
___ travel money for meetings, conferences
___ other _____
___ none at this time

B. Indicate the kinds of support your MCH program provides to *family organizations* (check all that apply):

___ in-kind services

___ providing space
___ clerical support (for newsletter, mailings, etc.) please specify _____
___ special projects (please specify) _____
___ grants (please specify) _____
___ other _____
___ none at this time

C. Please indicate the type of relationship your MCH program has with *family organizations* in your state.

Family Organization (Examples:Parent Teacher Association, La Leche League, parents of teens, Sudden Infant Death Syndrome, etc)	Type of Relationship		Comments
	Formal	Informal	
Family Voices			

VII. Family members who are paid *staff or consultants* employed in your MCH program for their *expertise as families*. (*Please note contact person/phone number/email address for web-based repository materials _____)*

FAMILY MEMBERS AS STAFF (not consultants)

A. Please answer the following questions about family members who are paid staff.

1. How are family members employed? (If you have a large number of family staff, check all that apply)

___ Have not employed family members as paid staff at this time
(skip to question VII- B)
___ Title V employs family members as staff directly # _____employed
___ Title V employs family members as staff through another agency
(please specify agency_____) # _____employed

2. What is the work location for employed family staff (do not include consultants)

___ Title V program
___ state office ____regional or county office _____community office

___ Family or Parent Organization (please specify _____)

___ Home based

___ Other (please specify)

3. **What are job title(s) and description(s) your program uses for family staff?**

4. **Approximate number of hours (weekly) for paid family staff (check all that apply):**

___ full-time (30-40 hours/week)
___ part-time (10-29 hours/week)
___ less than 10 hours
___ other(specify)

5. **Please indicate average salary range based on full time yearly equivalent (FTE) (check all that apply):**

___ less than $15,000
___ $15,001-$30,000
___ $30,001 – $45,000
___ other (specify) _____

6. **Employment Activities – Please indicate which of the following activities are important components of family staff's jobs.**

___ Providing direct, non-medical services, information, or support to families. (Examples – parent information and referral, parent to parent information or links, problem-solving, resource identification.)

___ Providing a parent/family perspective to Title V. (Examples – review of program materials, attending Title V meetings to offer family input, providing technical assistance or trainings on family centered care, cultural competence, representing a family viewpoint.)

___ Program development and planning for families. (Examples – developing materials and curricula for families, organizing family meetings and conferences, setting up or overseeing parent to parent programs, organizing family groups, developing and maintaining statewide family support programs, outreach to families – especially underserved groups.)

___ Encouraging or facilitating collaboration between families/family organizations and state Title V programs. (Examples – encouraging coalition-building, acting as a catalyst for health care reform efforts, increasing communication and collaboration with family groups and Title V.)

___ Supervising other family members or staff employed by Title V. (Examples: recruiting, orienting, training, mentoring, and evaluating.)

___ Other_____

FAMILY MEMBERS AS CONSULTANTS (not staff)

B. Please answer the following questions regarding family members as consultants.

1. **Does your MCH Program employ families as consultants?**
___ Have not employed family members as consultants in the past year. *(skip to question VII-C)*
___ Title V employs family members as consultants directly # ___employed
___ Title V employs family members as consultants through another agency
(please specify _____) # _____employed

2. **What are job title(s) and description(s) your program uses for family members as consultants?**

3. **Please indicate the average hourly consultant fee (check all that apply):**
___ less $10/hour
___ $11-$15/hour
___ $16-$20/hour
___ more then $20/hour

C. Please indicate whether paid family staff and family consultants receive (check all that apply):

___ Orientation for newly hired family staff or consultants
___ Mentorship for newly hired family staff or consultants
___ Evaluation and assessment of family staff or consultants

D. Based on obstacles or benefits your program has encountered, what suggestions would your program make to others who are considering hiring family members?

VIII. Are there any other particular strategies your program uses, which you have not already mentioned to obtain the input of underrepresented, underserved populations?

IX. What technical assistance might your MCH program need to foster greater family involvement? _____

From whom? ___MCHB ____Family Voices ___other states _____other

_____